The Michigan Cancer Consortium Initiative Strategic Plan for Implementation

Public and Private Partners Working Together to Achieve Cancer Control Priorities for Michigan

1998 - 2002

A project of the Michigan Cancer Consortium, the Michigan Department of Community Health, and their community health partners

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Introduction

The Michigan Cancer Consortium Initiative is a new and innovative approach to comprehensively fighting cancer through prevention, early detection, treatment, rehabilitation, and palliation.

The initiative is built upon an exciting and ambitious concept in which public and private partners are working together to achieve 10 current cancer control priorities for the state of Michigan.

Nine action plans have been developed and are summarized here; these will guide implementation of the priorities. These plans capture the best thinking of cancer control experts, health care providers, and community leaders in our state.

The driving force behind the initiative is the Michigan Cancer Consortium. Since its inception in 1987, the consortium consistently has been at the forefront of cancer prevention and control efforts. In fact, officials of the Centers for Disease Control and Prevention recently hailed the consortium and its accomplishments as a model for the nation.

The cornerstone of the Michigan Cancer Consortium's current efforts is the Michigan Cancer Consortium Initiative, a project with three main goals:

1) to significantly reduce cancer morbidity and mortality in Michigan;
2) to establish and maintain a collaborative process to identify and achieve cancer control priorities; and
3) to achieve cost-effective resource utilization for cancer control.

The History of the Initiative

At its inception, the Michigan Cancer Consortium consisted of a statewide network of cancer organizations and experts working together to advise the state health department in its cancer prevention and control efforts. Between 1987 and 1996, the consortium and the Michigan Department of Community Health (formerly the Michigan Department of Public Health) combined efforts to accomplish a number of objectives, making great strides in cancer control.

In 1996, after years of working together, the consortium and the department agreed that there was a pressing need in Michigan for a systematic, comprehensive, statewide cancer control effort that could identify cancer-related problems, objectives, and priorities, then form partnerships capable of implementing the priorities and evaluating the outcomes.

In response, the Michigan Cancer Consortium broadened its membership base to include not only cancer organizations, but also other health care organizations.

It also accepted a new charge – that of providing leadership and a forum for the development of a statewide plan that would be implemented through the collaborative efforts of many different players – cancer centers and experts; health care providers, delivery systems, organizations, agencies, and insurers; community-based organizations; business; labor; and consumers – not just the state health department.

Members of the consortium's six expert advisory committees (one each for breast, cervical, colorectal, lung, and prostate cancer, and one for the primary prevention of cancer) set to work on the new concept.

They reviewed the existing literature and data and considered related epidemiology, prevention, screening and early detection, diagnosis, treatment, post-treatment, quality of life, and economic issues.

Based upon that work, each advisory committee forwarded recommendations to the consortium, detailing what they believed to be the most important interventions that would reduce cancer incidence, morbidity, and mortality in our state.

Using criteria that focused on the importance of starting implementation during the next few years and the need for inter-agency collaboration to achieve the objective, the consortium prioritized these recommendations. In June 1998, it chose 10 cancer control priority objectives for the 1998-2002 period and launched the Michigan Cancer Consortium Initiative.

Public and private partners quickly joined together and formed action planning groups to develop strategic action plans to achieve the 10 target priorities. In April 1999, they submitted their completed action plans.

These strategic plans represent the collective wisdom of a wide range of individuals and organizations in our state, from nationally recognized cancer experts to state health care leaders to health care providers to insurers to representatives of community-based organizations, all working together to achieve a common objective.

Every member organization of the consortium has endorsed the priorities in these plans and has committed to participate in the implementation of at least one of them. The implementation phase of the initiative is ready to begin.

What's Next

Consortium leaders and consortium staff from the Michigan Department of Community Health are in the process of identifying common strategies across the nine plans. Methods are being developed to facilitate the coordination of these cross-plan strategies and, thus, maximize the use of both tangible and intangible resources during the implementation phase.

This fall, the consortium will contact both public and private organizations throughout the state of Michigan to discuss the initiative and to work with them to commit to help implement specific strategies within the nine strategic action plans.

Resource development specialists from Michigan Cancer Consortium member organizations and other health agencies are working to identify and secure potential sources of funding to support the implementation phase of the initiative.

It is anticipated that funding will come from numerous sources, including foundations, corporations, voluntary organizations, and federal and state governmental agencies. In addition, Michigan Cancer Consortium member organizations and partners are making commitments to contribute staff, volunteers, and other resources toward the realization of the Michigan Cancer Consortium Initiative goals.

The development and implementation of the Michigan Cancer Consortium Initiative are exciting steps, not only for the health care professionals and community representatives who have dedicated countless hours to the project, but for all the citizens of our state.

The Michigan Cancer Consortium Initiative truly is a groundbreaking effort with far-reaching impact.

Its goals will be accomplished through the cooperative, collaborative efforts of dozens of public and private partners throughout our state. It is expected to produce a synergy statewide and at the community level and to have an overall impact far greater than that which might have been accomplished by these agencies, organizations, and individuals working independently of one another.

By working together, we truly will make a difference in the health and quality of life in our state. We will be taking great strides toward eliminating the social, personal, and economic costs that cancer imposes on our

families, friends, and neighbors and together, we will realize a healthier tomorrow for all our citizens.

We invite you to join with us in this important effort. If you would like more information about the initiative and how you can become involved, or if you would like to receive detailed Michigan cancer burden data, contact Michigan Cancer Consortium Initiative Coordinator Sue Haviland, M.S.N., at 517-335-8372.

10 Priority Objectives of the Michigan Cancer Consortium Initiative

Breast Cancer:

By 2003, 80 percent of women will receive information on risk-appropriate preventive services and age-appropriate annual breast cancer screening with clinical breast examination and mammography, with appropriate treatment and follow-up of positive findings.

Cervical Cancer:

By 2005, the proportion of Michigan women in high-risk populations who have Pap smears according to evidence-based guidelines and who received appropriate follow-up of abnormal screening results will be 90 percent.

Colorectal Cancer:

By 2004, increase to 50 percent the proportion of average-risk people in Michigan who have received appropriate colorectal cancer screening and appropriate follow-up of abnormal screening results.

Lung Cancer:

By 2010, reduce the overall Michigan adult (18+) smoking prevalence by 42 percent and adult per capita consumption by 25 percent.

By 2010, reduce the proportion of Michigan youth grades 9-12 who report smoking cigarettes during the past 30 days to 22 percent.

Prostate Cancer:

By 2002, prostate cancer patients will have their knowledge and understanding of prostate cancer, treatment options, side effects, and quality-of-life issues measured by patient surveys, with findings used to develop patient education activities.

Clinical Cancer Trials:

By 2005, double the number and increase the diversity of participants enrolled in clinical cancer research.

Clinical and Cost Data:

By 2005, develop the linked economic and clinical database infrastructure necessary to support data-driven decisions for control of breast, cervical, colorectal, lung, and prostate cancers within the state of Michigan.

End-of-Life:

By 2005, increase the timeliness of referrals to end-of-life care for breast, cervical, colorectal, lung, and prostate cancer patients.

Standardized Lexicons:

By 2005, develop and disseminate standardized pathology protocols and reporting formats for examination of cancerous tissue specimens and determine the need for similar surgical reporting formats that include data important in making breast, cervical, colorectal, lung, and prostate cancer treatment and prognostic decisions.

Breast Cancer: Increasing Rates of Screening and Use of Preventive Services

Goal: ***By 2003, 80 percent of women will receive risk-appropriate preventive services and age-appropriate annual breast cancer screening with clinical breast examination and mammography, with appropriate treatment and follow-up of positive findings.***

Why This Goal Is Important

In 1995, there were 6,131 new cases of breast cancer diagnosed in Michigan women.[1] Of those, 60.7 percent were found at the localized stage, a stage at which women statistically have a 96.8 percent chance of surviving five years.

Another 26.0 percent were diagnosed at the regional stage, when women statistically have a 75.9 percent chance of surviving five years; 3.8 percent were diagnosed at the distant metastasis stage, when women statistically have a 20.6 percent chance of surviving for five years.

It is generally agreed that an increase in the use of screening mammography has led to earlier diagnoses and, as a result, fewer deaths from breast cancer.

Yet, despite this knowledge, 1,538 women in our state lost their lives to breast cancer in 1997. In fact, during the 1992-1996 period, Michigan women lost a total of 156,344 years of life to breast cancer, with an average of 19.1 years of life lost *per woman dying.*

In 1996, Blue Cross Blue Shield of Michigan paid $22.5 million in claims for its regular Michigan subscribers for all phases of treatment of breast cancer (an average of $7,569 per case). During the same period, Medicare Part A paid a total of $6.8 million (an average of $3,550 per Michigan case).

These sums do not include significant out-of-pocket payments for deductibles, co-payments, medications, transportation, and other non-covered items. Likewise, they also do not reflect the lost wages and opportunity costs suffered by these women and their families.

Who's at Greatest Risk?

It is well-known in the health care community that appropriately timed breast cancer screening on a routine basis is the key to breast cancer prevention and control. For women aged 40 and older, this means annual clinical breast examinations and annual mammograms.

Although Michigan Behavioral Risk Factor Survey (BRFS) data have shown a statistically significant increase in the proportion of Michigan women aged 40 and older who receive appropriately timed breast cancer screening (55.4 percent in 1997 vs. 49.5 percent in 1991),[2] the fact remains that a large percentage of our state's female population is not receiving breast cancer screening at the recommended intervals. Obviously, much work remains to be done.

Some population groups are less apt than others to seek and receive routine screening.

For instance, although the risk of breast cancer increases with age, the rate of appropriately timed breast cancer screening tends to decrease with age.

Preliminary 1998 BRFS estimates indicate that while 62.1 percent of Michigan women aged 50-64 said they were receiving appropriately timed breast cancer screening, only 45.2 percent of Michigan women aged 65 and older reported that they were receiving appropriately timed breast cancer

screening. Data also show that rates of appropriately timed breast cancer screening tend to lower as household income decreases.

For instance, preliminary estimates from the 1998 BRFS indicate that only 29.1 percent of all Michigan women aged 40 and older with a household income below $10,000 received age-appropriate breast cancer screening.

What Needs to be Done

To lower breast cancer incidence and mortality rates, we must deal with the barriers to screening and follow-up services.

To do so, we must first understand who is (and is not) receiving age-appropriate breast cancer screening and why. Once we understand those factors, we can devise and implement strategies to educate the public and providers about the need for breast cancer screening on a routine basis and the types of preventive services available.

The Michigan Cancer Consortium's Breast Cancer Action Group has devised a strategic action plan that includes numerous opportunities for people from high-risk populations to work side-by-side with representatives of medical specialities, nursing, allied health professional groups, voluntary health organizations, health care systems, public health entities, and other interested parties to assess the situation in our state and develop and implement strategies that will increase breast cancer screening rates and the use of preventive services, especially among women who are most at risk for developing breast cancer.

Specifically, the group's strategic plan recommends the following actions be taken.

***Objective #1*: By 2003, 80 percent of women (as measured by the Michigan BRFS) will receive age-appropriate annual breast cancer screening.** *(NOTE: Full implementation of this goal assumes the responsible provider will treat or refer for appropriate treatment and follow-up of positive findings.)*

To determine who's not being screened and why: The BRFS and other data sets should be used to compile data on women being screened (and not being screened) for breast cancer and to document possible barriers to screening.

To do this, the BRFS should be amended to add questions to determine whether (and how often) mammograms and clinical breast exams are covered through health care plans and why women are not being screened at the recommended frequencies or are not being screened at all.

Data from the various health care plans operating in Michigan should be gathered to supplement this BRFS data.

Data from all sources should be compiled and analyzed to determine the patient characteristics, geography, and insurance status of women being screened and not being screened on a routine basis. This analysis should be done on an annual basis and the relevant findings should be disseminated to health care providers.

To educate providers and the public about the need for screening: A four-pronged educational plan should be developed and deployed to address the necessity for all Michigan women to have annual screening mammograms and clinical breast examinations.

The first three portions of the plan should be designed for health care providers, the public, and the media. The fourth component should focus on Breast Cancer Awareness Month, which involves providers, the public, and the media.

Providers should be furnished with both professional education materials and patient education materials, and also should receive support in providing breast cancer screening to hard-to-reach populations.

Public education materials on breast cancer screening should be developed and made available to the public through providers and community and social groups.

Press kits, public service announcements, posters, and other marketing materials should be developed and disseminated to the media with an explanation of the importance of breast cancer screening and a request to help educate the public, especially members of target population groups.

Breast Cancer Awareness Month activities should continue each October and community-based organizations, health care plans, providers, businesses, and the media all should be urged to work together to help publicize the importance of women receiving age-appropriate breast cancer screening services.

To increase the accessibility and responsiveness of health systems: The Michigan Breast and Cervical Cancer Control Program (BCCCP) should be expanded to reach more at-risk women.

Resources should be sought and obtained to reopen the BCCCP to women eligible for Medicare, thus increasing the number of older and disabled women who can receive screening through the program.

The BCCCP also should be opened fully to women under the age of 40 who are at high risk for breast cancer or who are symptomatic.

Accessibility to convenient, flexible screening services should be increased throughout Michigan.

Employers should be encouraged to operate worksite wellness programs that encourage employees to achieve and maintain good health through screening and other measures and that offer satellite and mobile screening clinics.

All women should have access to clinical breast examination and mammography within 30 miles or 30 minutes of home, and community transportation services and systems should be adapted or instituted to offer women breast cancer screening and follow-up appointment transportation at no cost or low cost to the women.

Health care systems and providers should be encouraged to offer screening and follow-up service appointments at flexible, non-traditional hours.

Health professional licensing boards should be encouraged to have providers receive continuing education or continuing medical education in cancer screening updates every three years.

The 10 largest health care insurers in Michigan (including public insurers and managed care plans) should be encouraged to cover age-appropriate annual breast cancer screening with clinical breast examination and mammography and to encourage women in their plans to receive such care.

Objective #2: By 2003, 80 percent of women will receive information on risk-appropriate preventive services for breast cancer.

Women should receive information to help them understand their risk of developing breast cancer and their choices regarding risk-appropriate preventive services.

Health care providers routinely should be given information on the most current risk assessment tools, as well as information based upon the results of clinical trials of risk-appropriate services.

Providers should implement programs to provide information on risk-appropriate preventive services that will meet the needs of the populations they serve.

The BRFS should be amended to add questions that can be used to help determine the proportion of women receiving information on risk-appropriate preventive services over time. Outreach and educational efforts should be adjusted accordingly.

Endnotes:

1. Whenever possible, the data quoted in this report are the most recent available. Frequently, there is an 18- to 24-month interval between the time a cancer is diagnosed and the time that information is available from the Michigan Cancer Registry. However, cancer mortality data for any given year generally are available from the Registry within several months after the close of that calendar year. Hence, the cancer-related mortality data that are available often are more recent than the available cancer-related incidence data.

2. In mid-1997, the American Cancer Society (ACS) changed its guidelines for appropriate breast cancer screening to annual clinical breast examinations (CBEs) and annual mammograms for all women aged 40 and older. The ACS' previous recommendation was CBEs every year and mammograms every one to two years for women aged 40-49, and annual CBEs and annual mammograms for women aged 50 and older. Future calculations of appropriate breast screening percentages as noted in the BRFS will be based upon annual CBEs and annual mammograms for all women aged 40 and older and, therefore, will not be comparable to the figures cited here.

Cervical Cancer: Increasing Rates of Screening and Follow-Up

Goal: ***By 2005, the proportion of Michigan women in high-risk populations who have Pap smears according to evidence-based guidelines and who receive appropriate follow-up of abnormal screening results will be 90 percent.***

Why This Goal Is Important

Death from cervical cancer is considered to be essentially preventable, and no one should be dying of cervical cancer anymore.

Yet, 122 Michigan women died from this disease in 1997 alone.[1]

In 1995, there were 423 new cases of invasive cervical cancer, more than one-quarter of which were diagnosed at the regional stage, a stage at which these women statistically have only a 49 percent chance of surviving five years.

In addition, seven percent of new cervical cancer diagnoses are at the distant metastasis stage, a stage at which women statistically have only a nine percent chance of surviving for five years.

During the 1992 and 1996 period, Michigan women lost a total of 20,148 years of life to cervical cancer, with an average of 25.7 years of life lost *per woman dying.*

Cervical cancer also is expensive in monetary terms. During 1996, Blue Cross Blue Shield of Michigan paid a total of $2.6 million on claims for its regular subscribers for all phases of treatment of cervical cancer (an average of $7,792 per case). During that same period, Medicare Part A paid a total of $787,475 (an average of $5,877 per case).

These sums do not include significant out-of-pocket payments for deductibles, co-payments, medications, transportation, and other non-covered items.

Likewise, they also do not reflect the lost wages and opportunity costs suffered by these women and their families.

Most cervical cancers develop over a relatively long period of time through a series of gradual, well-defined pre-cancerous lesions. During this process, abnormal tissue can be detected easily by a Pap smear and then removed by a clinician.

Evidence strongly suggests that regular screening with Pap smears decreases mortality from cervical cancer.

Experts believe that virtually all cervical cancer deaths could be prevented by a combination of safe sex practices, routine Pap smears, and appropriate follow-up of abnormal screening results. Yet, research indicates that certain groups of women do not get regular Pap smears.

Case-control studies have shown that the risk of developing invasive cervical cancer is three to 10 times greater in women who have not been screened. Data also indicate that the risk of developing cervical cancer increases as the time since the last normal Pap smear increases or as the frequency of screening decreases.

Who's at Greatest Risk?

Women at risk of developing cervical cancer are the ones who are – or who ever have been – sexually active and who are not being screened on a routine basis for cervical cancer.

Research has shown that women from minority groups, especially populations of color, are at particular risk for the disease, as are rural and urban women for whom access to routine health care services is, at best, a challenge and, at worst, non-existent.

It is generally agreed that the most important risk factor for cervical cancer is infection by human papillomavirus (HPV). In fact, HPV DNA is present in 93 percent of cases involving cervical cancer and its precursor lesions. Although there currently is no cure for HPV infection, providers can treat the warts and abnormal cell growth caused by these viruses and prevent them from developing into cancer.

Certain types of sexual behavior increase a woman's risk of becoming infected with HPV. Among them are having intercourse at an early age, having numerous sexual partners, and having unprotected sexual contact at any age.

What Needs to be Done

To lower cervical cancer incidence and mortality rates, we must deal with the barriers to screening, whether these are patient barriers, provider barriers, and/or health care system barriers. We also need to better understand who is getting cervical cancer and why.

To those ends, the Michigan Cancer Consortium's Cervical Cancer Action Planning Group has devised a strategic action plan that includes numerous opportunities for people from high-risk populations to work side-by-side with representatives of medical specialities, nursing, allied health professional groups, voluntary health organizations, health care systems, public health entities, and other interested parties to address these barriers.

The Cervical Cancer Action Group believes that accomplishment of the following strategies will have a positive and lasting impact on the health of the affected populations and, ultimately, will lower the social, personal, and economic tolls that cervical cancer exacts on the citizens of Michigan.

To Address Patient Barriers: A variety of personal factors help explain why some women do not seek routine screening for cervical cancer.

Some say they are too busy to be screened. Others believe they are not at risk, or may be operating under the assumption that a lack of symptoms means there is no need to get a Pap smear.

Some women may not know much about the procedure, or may be fearful of the technique or the potential findings.

Still others may not visit a primary care provider regularly enough to receive routine medical care that includes pelvic examinations.

A number of the women at particular risk for cervical cancer live under religious, social, or traditional norms that create barriers to cervical cancer screening.

All these issues must be addressed through education.

Objective #1: ***By 2003, the percentage of at-risk Michigan women who understand the need to be screened for cervical cancer on a regular basis throughout their lifetime and who have knowledge of cervical cancer screening guidelines will be 85 percent, as measured by appropriate survey tools administered within identified Michigan communities representing diverse at-risk groups.***

A culturally and linguistically appropriate public education campaign should be launched to inform at-risk women about cervical cancer and why (and how often) they should be screened.

The campaign design should encompass patient-based, as well as culturally based, barriers to screening. Whenever possible, peer spokespersons should be used to share the educational messages with women in the targeted groups.

To Address Provider Barriers: Provider practices can become barriers to cervical cancer screening. For instance, they may not routinely recommend Pap smears, perhaps because they feel uncomfortable discussing cervical cancer and the need for screening.

Some providers may assume Pap smear scheduling is being managed by a woman's other health care provider(s). In fact, studies have shown that OB/GYNs are more likely to recommend Pap smears than primary care providers. Even if they do perform Pap smears, some providers may create barriers to optimum care and prevention by the fact that they have no active follow-up procedure for abnormal Pap smear results, or that they sometimes make assumptions about the sexual activities of some patients.

In addition, fundamental factors, such as the lack of agreement among some health care providers about the appropriate schedule for cervical cancer screening or even how important cervical cancer prevention is, create barriers.

All these barriers must be addressed.

Objective #1: ***By 2003, the proportion of Michigan primary care providers who actively recommend and/or perform routinely scheduled Pap smears according to current guidelines and adhere to standard protocol for follow-up of abnormal screening results will be 95 percent, as measured by an appropriate post-intervention survey of providers.***

Primary care providers, nurse practitioners, physician assistants, and students in medical-related programs should be educated about cervical cancer screening recommendations, the protocol for follow-up of abnormal screening results, and the recommended systems for patient follow-up.

Medical personnel should be educated about which populations are at highest risk for the disease and what factors place them at high risk.

Objective #2: ***By 2002, improve the effectiveness of cervical cancer screening within Michigan by reducing the rate of false negative Pap smears to within acceptable parameters, as measured by an appropriate post-intervention survey.***

A group of experts should be assembled to determine acceptable parameters for the rate of false negative Pap smears. Statewide consensus regarding Pap smear sampling techniques and technologies should be obtained from clinical experts and key professional organizations.

Professional education materials using this information should be developed and disseminated to health care professionals and students in medical-related programs.

To Address Health Care System Barriers: Health care systems also pose barriers to cervical cancer screening. For instance, health care service sites may not be accessible to all women, particularly women with physical disabilities.

Similarly, because of the lack of universal agreement about the appropriate schedule for cervical cancer screening or even about the importance of cervical cancer prevention itself, health care systems may not emphasize cervical cancer prevention.

The costs of having a Pap smear and getting follow-up care, if needed, is a barrier to uninsured women who, as a group, are less likely than insured women to have up-to-date screenings.

Likewise, few or no geographically accessible providers or service sites pose a barrier for some women, and the lack of culturally sensitive providers and services present a significant barrier for others.

These barriers must be overcome.

Objective #1: ***By 2004, increase access (cultural, geographic, financial, and barrier-free) to cervical cancer screening and follow-up services within the state.***

Provider practices, health care organizations and systems, managed care organizations, and health insurers should partner with community and cultural groups to address cultural barriers to cervical cancer screening.

Students in medical-related programs should be educated about the benefits of providing culturally and linguistically appropriate services.

Employers, community and cultural groups, provider practices, managed care organizations, health insurers, health care organizations and systems, government agencies, and other parties should help address geographic barriers to cervical cancer screening.

Additional public funding should be obtained to address existing financial barriers to screening among high-risk women.

All facilities offering cervical cancer services should be made barrier-free for women with disabilities.

Objective #2: By 2002, at least 90 percent of the women in Michigan prisons, jails, and mental health residential facilities will be routinely and appropriately screened for cervical cancer, according to current evidence-based screening and detection protocol.

Partnerships should be built with corrections and mental health systems to ensure that inmates and patients receive both appropriate and routine cervical cancer screening and follow-up of abnormal screening results from culturally sensitive providers.

Objective #3: By 2002, all managed care organizations and health insurers, both commercial and public, in Michigan will agree upon, comply with, and promote one set of cervical cancer screening and detection standards.

Managed care organizations and health insurers should be educated about the latest standards for cervical cancer screening and detection recommended by the Michigan Department of Community Health's Cervical Cancer Advisory Committee. They should be encouraged to approve regular cervical cancer screening and follow-up services and to establish cervical cancer screening and follow-up as a marker of quality care for all women.

To Address Research Needs: There is a need to further develop our knowledge about which women are at greatest risk of developing cervical cancer and why.

This expanded knowledge will enable us to not only better educate our providers and health care systems, but also will enable us to more accurately target our public education and outreach efforts among populations that are considered to be at particular risk for the disease.

We must improve our understanding of what barriers lie in the way of women who procrastinate and so don't receive screening at the recommended interval, as well as those women who are never screened for cervical cancer.

Objective #1: By 2001, identify the socio-demographic and geographic characteristics and describe the screening behavior of Michigan women who develop cervical cancer and/or who die of cervical cancer.

Following completion of a three-month feasibility study, a follow-back study of Michigan women who have been diagnosed with invasive cervical cancer or who have died of cervical cancer should be done to determine points of failure within the health care system and implications for designing strategies that will reduce the number of cervical cancer-related deaths in Michigan.

In addition, researchers should correlate identified socio-demographic characteristics of women who are at high risk of not being screened for cervical cancer with current demographic data to arrive at an estimate of

the number and location of Michigan women at high risk for not being screened.

Endnote:

1. Whenever possible, the data quoted in this report are the most recent available. Frequently, there is an 18- to 24-month interval between the time a cancer is diagnosed and the time that information is available from the Michigan Cancer Registry. However, cancer mortality data for any given year generally are available from the Registry within several months after the close of that calendar year. Hence, the cancer-related mortality data that are available often are more recent than the available cancer-related incidence data.

Colorectal Cancer: Increasing Rates of Screening and Follow-Up

Goal: ***By 2004, increase to 50 percent the proportion of average-risk people in Michigan who have received appropriate colorectal cancer screening and appropriate follow-up of abnormal screening results.***

Why This Goal Is Important

In Michigan, colorectal cancer is the fourth most commonly diagnosed cancer, with 4,620 new cases of colorectal cancer diagnosed in 1995.[1]

It is a cancer of both genders – men accounted for 50.2 percent of the new cases diagnosed in 1995, while women accounted for 49.8 percent.

Of the total cases diagnosed in the state that year, 33.7 percent were found at the localized stage, a stage at which individuals statistically have a 91.6 percent chance of surviving five years. Another 38.8 percent were diagnosed at the regional stage, when individuals statistically have a 63.8 percent chance of surviving five years; 15.5 percent were diagnosed at the distant metastasis stage, when there's a 7.3 percent chance of surviving for five years.

Colorectal cancer ranks second overall as a cause of cancer death in our state.

In 1997, 2,024 Michigan residents died from colorectal cancer. During the 1992-1996 period, Michigan residents lost a total of 138,101 years of life to the disease, with an average of 13.5 years of life lost per death.

Colorectal cancer takes a financial toll, as well. In 1996, Blue Cross Blue Shield of Michigan paid $14.9 million in claims for its regular Michigan subscribers for all phases of treatment of colorectal cancer (an average of $15,616 per case). During the same period, Medicare Part A paid a total of $47.3 million (an average of $14,195 per Michigan case).

These sums do not include significant out-of-pocket payments for deductibles, co-payments, medications, transportation, and other non-covered items.

Likewise, they also do not reflect the lost wages and opportunity costs suffered by these patients and their families.

Research has shown that most Michigan adults do not feel vulnerable to colorectal cancer. In fact, in a recent survey, only 5.8 percent of those surveyed said they believed they had a greater-than-average chance of developing the disease.

Survey data show that fewer than one out of five Michigan adults (17.9 percent) report having been screened using the proctoscopic exam (defined for purposes of the survey as an examination of the colon in which a tube is inserted in the rectum along the entire length of the colon).

Generally, Michigan adults who have a usual source of care, live in an urban area, have a higher income, and/or have health insurance are more likely to be screened for colorectal cancer.

Research indicates that detecting and removing polyps reduces the incidence of colorectal cancer and that detecting early-stage colorectal cancers lowers mortality from the disease.

The U.S. Preventive Services Task Force, the American Cancer Society, the Michigan Cancer Consortium, and the Michigan Colorectal Cancer Advisory Committee recommend colorectal cancer screening for all persons aged 50 and older. Effective methods include fecal occult blood testing (FOBT), sigmoidoscopy, colonoscopy, and double-contrast barium enema (DCBE).

Studies have shown that FOBT and diagnostic evaluation and treatment for positive results reduces colorectal cancer mortality by 15 percent to 33 percent, and that sigmoidoscopy is associated with a 59 percent to 80 percent reduction in risk of death from cancer in the part of the colon examined by the rigid sigmoidoscope.

Data from the 1997 Behavioral Risk Factor Survey show that 22.1 percent of Michigan residents age 50 and older reported having had an FOBT during the past year, while 35 percent reported having a sigmoidoscopy within the last five years.

Who's at Greatest Risk?

Lack of adherence to recommended screening guidelines places an individual at increased risk for colorectal cancer morbidity and mortality.

In addition, researchers comparing colorectal cancer incidence rates among racial and ethnic groups in the United States have found that cultural and socioeconomic differences such as lifestyle practices (e.g., dietary habits, use of tobacco and/or alcohol, reproductive history, physical activity, and high-risk occupations) also affect an individual's risks for the disease.

Recent epidemiologic studies support the protective role of dietary fiber, the harmful role of dietary fat (especially saturated fat from animal sources), and the possible protection that physical activity offers in preventing the development of colorectal cancer.

Genetic and environmental factors also may influence incidence rates, as may access to (and availability and utilization of) quality health care and preventive medical services.

Data from a 1997 survey of Michigan adults showed that poorly educated minorities are particularly unlikely to take preventive actions against colorectal cancer, partly because they believe such actions are unlikely to have any benefit.

What Needs to be Done

The men and women in our state must be educated about the fact that appropriate screening can detect polyps, that removal of polyps can prevent the development of colorectal cancer, and that colorectal cancer is curable if detected early.

The key to patients, consumers, and health plans being more receptive to colorectal cancer screening methods is for providers to understand and advocate the importance of proper early detection, as well as prevention education, especially for individuals who are age 50 and older.

The Michigan Cancer Consortium's Colorectal Cancer Action Planning Group has devised a strategic action plan to develop and implement strategies that will increase professional education, health plan commitment, and public education and awareness about colorectal cancer risks, prevention, and detection. Specifically, the group's strategic plan recommends the following actions be taken.

To Address the Need for Increased Professional Education: Studies of potential reasons for low cancer screening rates have emphasized the determining role of physicians who may, for various reasons, not recommend, provide, or facilitate access to screening examinations. The lack of physician advocacy may be due to disagreement with, or confusion about, colorectal cancer screening guidelines in average-risk individuals; concerns about safety and efficacy of testing; patient compliance; the absence of economic incentives; or logistical barriers arising from limited resources in a particular geographic area.

Objective #1: By 2002, increase the knowledge of colorectal cancer risk factors, screening guidelines, and appropriate follow-up of abnormal screening results

among currently practicing health care providers.

Colorectal cancer screening guidelines and information about preventive/risk factors and appropriate follow-up of abnormal screening results should be disseminated to practicing health care providers.

Among the educational vehicles that should be developed and disseminated are statewide conferences and continuing education offerings, fact sheets, papers in journals and newsletters, CD-ROMs, and laminated cards. In-office reminder systems should be developed and made available to keep providers aware of colorectal cancer screening anniversaries for appropriate patients.

Objective #2: By 2002, increase the skill level of health care providers who perform colorectal cancer screening and appropriate follow-up of abnormal screening results.

Continuing education opportunities should be provided statewide to health care providers to enable them to refine or develop colorectal cancer screening skills and knowledge of appropriate follow-up of abnormal screening results, and to provide them with sensitivity skills training that will enable them to recognize and respond to differences in patients' cultural values, traditions, and beliefs that may impact upon screening and follow-up scheduling and procedures.

Where professional guidelines for colorectal cancer screening and the follow-up of abnormal results found through screenings exist, all screening providers, including radiologists and endoscopists, should be informed about their content and encouraged to understand and use them. If professional screening and follow-up guidelines do not exist, they should be developed and disseminated, and all screening providers should be encouraged to understand and use them.

Objective #3: By 2002, improve the education of health care students regarding colorectal cancer screening and follow-up of abnormal screening results.

Medical school curricula should be reviewed and changed, if necessary, to increase the knowledge of health care students about the preventive and risk factors associated with colorectal cancer, as well as the guidelines for colorectal cancer screening and protocol for follow-up of abnormal screening results.

In addition, medical school curricula should be reviewed and changed, if necessary, to increase the "hands on" skill level of health care students related to colorectal cancer screening procedures and the appropriate follow-up of abnormal screening results.

Medical residency/internship requirements should include content on colorectal cancer screening guidelines, follow-up protocols, screening skill development, cultural sensitivity awareness, and effective communication.

To Address the Need for Increased Health Plan Commitment: The opportunity for providing preventive services requires consideration of economic, organizational and conceptual barriers.

Ultimately, the potential obstacles to achieving and sustaining an optimal level and quality standard of colorectal cancer screening in the average-risk population will be overcome by a coordinated effort in training health care professionals and educating the public.

In addition, agencies in both the public and private sectors must collaborate to ensure the allocation of sufficient resources for colorectal cancer screening and diagnosis.

Objective #1: Increase health plan commitment to colorectal cancer screening

by networking with Michigan's health plans to encourage them to incorporate colorectal cancer screening into their standards of care.

Health plans and other payers should be informed of the cost-effectiveness of colorectal cancer screening and the number of professional associations who support routine screening.

It is hoped that health plans and other payers will then commit to cover the cost of colorectal cancer screening for average-risk individuals and to promote colorectal cancer screening to these individuals.

Concurrently, national accreditation programs and regulatory bodies should be contacted to gain their commitment to include colorectal cancer screening in their performance measurement systems.

To Address the Need for Increased Public Education and Awareness:

Successful implementation of any recommended screening intervention requires that patients be fully informed about the screening process (i.e., preparation, procedure, and follow-up of positive results), as well as the potential benefits and risks.

Objective #1: By 2001, increase awareness of colorectal cancer risks, prevention, and testing for early detection, as evidenced by the Michigan Behavioral Risk Factor Survey.

Current public education initiatives that increase awareness of colorectal cancer risks, prevention, and testing for early detection should be gathered, studied, and evaluated for these uses.

A low-reading-level consumer brochure and a colorectal cancer education poster for clinics should be produced and distributed to providers and health care systems.

The Michigan State Medical Society, the Michigan Osteopathic Association, and local public health departments should be encouraged to participate in a Michigan Colorectal Cancer Awareness Campaign, which should be offered at flu shot clinics statewide in October 2000; campaign partners should receive copies of the public education brochure and other support materials to distribute.

A survey should be developed and sent to all internists/family practice providers in Michigan to assess the level of public interest generated by the colorectal cancer campaign. Results of the survey should be compiled and analyzed, and recommendations should be made regarding the feasibility of an annual, statewide colorectal cancer awareness campaign.

Endnote:

1. Whenever possible, the data quoted in this report are the most recent available. Frequently, there is an 18- to 24-month interval between the time a cancer is diagnosed and the time that information is available from the Michigan Cancer Registry. However, cancer mortality data for any given year generally are available from the Registry within several months after the close of that calendar year. Hence, the cancer-related mortality data that are available often are more recent than the available cancer-related incidence data.

Tobacco: Reducing Smoking Prevalence and Consumption Among Adults and Youth

Goals: ***By 2010, reduce the overall Michigan adult (18+) smoking prevalence by 42 percent and adult per capita consumption by 25 percent.***

By 2010, reduce the proportion of Michigan youth grades 9 - 12 who report smoking cigarettes during the past 30 days to 22 percent.

Why These Goals Are Important

Tobacco use is the most preventable cause of disease and death in our society and the leading cause of cancer death for Michigan men and women. It is linked to the top five major causes of death in the United States: heart disease, cancer, stroke, emphysema, and unintentional injuries.

Experts estimate that tobacco use is related to more than 416,000 deaths in the United States each year, including 30 percent of all cancer deaths (90 percent of all lung cancers).

In Michigan alone, 5,543 people died from lung cancer during 1997.[1]

Tobacco use has been linked to many fatal and non-fatal cancers, including those of the mouth, pharynx, larynx, esophagus, pancreas, uterine, cervix, kidney, and bladder. Tobacco use also has been linked with increased mortality due to breast and prostate cancer.

Tobacco use places a significant economic burden on our society. In fact, estimates completed by the Michigan Department of Community Health Tobacco Program using the Smoking Attributable Morbidity, Mortality, and Economic Costs 3.0 computer program indicate that direct medical care costs in Michigan attributable to smoking were nearly $2.5 billion in 1993.

Ninety percent of current adult smokers started smoking when they were teenagers. Preliminary estimates from the 1998 Michigan Behavioral Risk Factor Survey indicate that 40.7 percent of young adults between the ages of 18 and 24 smoked.

Data from the 1997 Michigan Youth Behavioral Risk Factor Survey show that 75 percent of students in grades 9-12 said they had tried cigarettes and 38 percent said they currently smoked.

According to the Centers for Disease Control and Prevention, 15 percent of Michigan male high school students also use spit tobacco.

Who's at Greatest Risk?

Preliminary 1998 BRFS estimates indicate that 27.5 percent of the adults living in Michigan smoke, with the highest rates of tobacco use occurring among those population groups with low income and low educational levels.

Since 1994 when Michigan's tobacco tax was increased from 25 cents per pack to 75 cents per pack, there has been a substantial decrease in the quantity of tobacco consumed in the state.

Evidence from Michigan's BRFS suggests that smokers are smoking fewer cigarettes on each day, and that the number of persons smoking less often than once a day has increased. However, the survey has provided no evidence of a measurable decrease in the percentage of people who smoke.

BRFS data indicate that men smoke at higher rates than women (preliminary 1998 BRFS estimates show that 29.8 percent of

men in the state smoke vs. 25.4 percent of women); they also indicate that women have been quitting smoking at a far lower rate than men. In fact, lung cancer now has surpassed breast cancer as the leading cause of cancer death for women.

Immigrants and migrants that come to Michigan from countries with cultural traditions that promote tobacco use may have higher smoking rates and higher incidence of tobacco-related diseases.

Native Americans, including pregnant Native American women, also have a higher prevalence of tobacco use; studies of Native American communities have shown tobacco use rates of as high as 42 percent to 57 percent.

Tobacco use among low-income, underserved communities can be viewed as a response to stressful environmental conditions, and often is seen in conjunction with other health risk behaviors, such as alcohol abuse.

The Environmental Protection Agency has classified environmental tobacco smoke as a Group A carcinogen, meaning it has been known to cause cancer in humans.

Studies show a direct relationship between exposure to environmental tobacco smoke and adverse health effects in non-smokers, and a firm causal relationship has been established between lung cancer and mainstream smoke (i.e., smoke that is exhaled by the smoker).

Non-smokers living in homes with smokers face a higher risk of disease, including a 30 percent higher risk of getting lung cancer than those individuals who do not live with smokers.

What Needs to be Done

Because there are myriad determinants of tobacco use, there is a need for multiple strategies to address it. To significantly reduce smoking prevalence, initiatives must be undertaken that involve public policy-based, health care-based, and community and organization-based strategies and actions.

To that end, members of the Michigan Cancer Consortium Tobacco Action Planning Group have developed a strategic action plan that provides numerous opportunities for representatives of medical specialities, nursing, allied health professional groups, voluntary health organizations, health care systems, public health entities, the legislature, community groups and organizations, employers, and other interested parties to work side-by-side with people from high-risk populations to help lower the rate of smoking prevalence in our state between now and the year 2010.

Their action plan includes the following specific objectives.

Regarding Public Policy:

Objective #1: Establish a more comprehensive tobacco control program for Michigan that has adequate, ongoing funding.

The Michigan Cancer Consortium will participate in efforts to secure new funding from federal, state, and private sources to help bolster the state's tobacco control efforts. The consortium also will support, as appropriate, the efforts of other organizations to secure continuing or new funds from a variety of sources for tobacco control programs.

Objective #2: Eliminate the public's exposure to secondhand smoke in workplaces, restaurants, and all other facilities used by the public.

Employers, facility owners, and business associations and managers should be educated and encouraged to adopt voluntary policies that eliminate smoking or restrict it to enclosed, separately ventilated areas that nonsmokers are not required to enter.

Tobacco control advocates should urge the enactment of rules proposed by the Occupational, Safety and Health

Administration in 1994 that incorporate the standard of a smoke-free workplace and regulate tobacco in the same manner as all other hazardous materials in the workplace.

Objective #3: Support efforts to enforce current laws preventing the sale of tobacco to youth.

Efforts by retailers and local community-based organizations to restrict youth access to tobacco should be encouraged and supported. The Michigan Department of Community Health contract with the Food and Drug Administration to enforce federal rules against retail sales of tobacco products to minors should be supported by local health departments and local law enforcement agencies.

Efforts by law enforcement and regulators to restrict youth access to tobacco should be encouraged and supported.

Objective #4: Eliminate marketing practices that encourage children to use tobacco products.

Support efforts to eliminate point-of-sale, billboard, poster, or other tobacco advertising in any retail establishment, arena, or other public accommodation in which minors less than 18 years of age are permitted; and eliminate the sale or distribution of non-tobacco products carrying logos, brand names, or other graphics and messages intended to advertise or promote the use of tobacco.

Objective #5: Encourage all health care purchasers to provide patients access to high-quality smoking cessation services, consistent with Agency for Health Care Policy and Research clinical practice guidelines.

Michigan Cancer Consortium members should work to encourage smoking cessation interventions, counseling, and Food and Drug Administration-approved medication as covered services. The consortium also should encourage the establishment of a performance measure for health plans, similar to the measure for immunizations, to meet standards for smoking cessation.

Objective #6: Encourage licensed substance abuse agencies and the Michigan Certification Board of Addiction Professionals counselors to incorporate smoking cessation into their counseling.

Professional education activities should be conducted to encourage licensed substance abuse agencies and counselors to integrate tobacco cessation activities into their practices.

Regarding Health Care:

Objective #1: Integrate tobacco control into the education of health professionals in Michigan.

A uniform tobacco-related curriculum should be developed and integrated into all health professionals' preparation at the graduate level in Michigan.

Resource materials on tobacco curriculum development should be collected and evaluated, content and hours for Michigan curricula should be developed, and a clearinghouse should be established to disseminate these resources to health professional schools.

Funding should be sought and obtained to support multi-disciplinary health education initiatives to develop and implement an integrated curriculum concerning the reduction of the health consequences of tobacco use.

Medical, nursing, dental, pharmacy, and physician assistant schools in Michigan, as well as mental health training programs in the state, should be invited to help develop a core and discipline-specific curriculum, implementation plans, and evaluation methodology. Priority should be given to multi-disciplinary projects targeting high-risk populations.

Objective #2: Integrate tobacco control interventions into the clinical practice of all health professionals in Michigan through a broad approach aimed at health plans, hospitals, individual providers, and purchasers/insurers. Encourage inclusion of tobacco assessment, counseling, and treatment by insurers and providers that sell services.

Michigan hospitals and health plans should be encouraged to develop and implement systems for tobacco control in clinical practice.

Health plans should be encouraged to deliver effective smoking cessation treatments in all health care settings, and should include these interventions among the defined duties of their salaried clinicians. They also should be encouraged to implement and evaluate an integrative tobacco intervention system.

Primary care providers should receive training and resources and be encouraged to provide consistent delivery of tobacco control interventions.

Tobacco control also should be promoted through health care purchasers and payers.

Regarding Communities and Organizations:

Objective #1: Develop effective, state-of-the-art tobacco use prevention programs and make them available to schools and communities throughout Michigan.

Programs currently in use should be assessed against current "best practice" standards. The results of the assessments should be disseminated, along with guidance materials on how to incorporate the programs that have met the standards into the Michigan Model, to school districts and communities throughout the state.

Objective #2: School-based curricula should be supported by other community-based tobacco use policies and programs.

Strict enforcement of a no-tobacco-use policy on school property, at all school-sponsored events, and in other community facilities used by youth should be promoted and supported, as should tobacco use prevention programs in other organizations and groups providing recreational, athletic, educational, or social opportunities for youth.

Strict enforcement of laws and regulations prohibiting the sale of tobacco products to minors should be promoted and supported.

Tobacco use cessation programs for addicted youth who wish to quit smoking or using spit tobacco should be promoted and publicized.

Objective #3: Continue to promote and support tobacco use reduction activities among community based organizations, with special emphasis on those serving people of color and other groups at disproportionate risk of injury from tobacco.

A diverse array of opinion leaders, organizations, and groups should be educated and engaged in the tobacco control effort. Effective use of the existing network of local tobacco use reduction coalitions should be promoted and supported.

Efforts such as the Michigan Department of Community Health's Communities of Color Initiative should be promoted and supported. Other tobacco use reduction efforts by community-based organizations that serve, and are reflective of, persons of color and other high-risk groups also should be promoted and supported, as should the delivery of services for cessation, prevention, and protection from secondhand smoke to ethnically diverse populations in culturally competent and appropriate ways.

Endnote:

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Prostate Cancer: Increasing Public Awareness of Treatment Options, Side Effects, and Quality-of-Life Issues

Goal: ***By 2002, prostate cancer patients will have their knowledge and understanding of prostate cancer, treatment options, side effects, and quality-of-life issues measured by patient surveys, with findings used to develop patient education activities.***

Why This Goal Is Important

Since 1987, more Michigan men have been diagnosed with prostate cancer than with any other single type of cancer.

Michigan's mortality rate from prostate cancer ranks among the highest in the world.

Data indicate that roughly 14 percent of Michigan men will be diagnosed with prostate cancer sometime during their lives, and about 3 percent of men living in Michigan will die of this disease.

In 1995, there were 6,232 new cases of prostate cancer in Michigan, and the age-adjusted incidence rate of prostate cancer in Michigan was 133.8 cases per 100,000 men.[1]

During the 1992-1996 period, Michigan residents lost a total of 58,117 years of life due to prostate cancer, with an average of 9.1 years of life lost per death.

In 1997 alone, a total of 1,243 Michigan men died as a result of the disease.

In 1996, Blue Cross Blue Shield of Michigan paid $16.1 million on claims for its regular Michigan subscribers for all phases of treatment of prostate cancer, an average of $10,515 per case, and Medicare Part A paid an average of $5,475 per Michigan case.

These sums do not include significant out-of-pocket payments for deductibles, co-payments, medications, transportation, and other non-covered items.

Likewise, they also do not reflect the lost wages and opportunity costs suffered by these men and their families.

Part of the human toll taken by prostate cancer is the sense typically experienced by newly diagnosed patients of a loss of personal control over their lives. However, this can be remedied by ensuring that newly diagnosed cancer patients are provided with accurate and timely information about their diagnosis and the various treatment options they have (including the benefits, drawbacks, and side effects of each).

By arming themselves with this type of information, newly diagnosed men can adapt to their diagnosis and once again begin to take an active role in decisions about their care and the ways in which they will live their life.

Investigators have shown that there are significant benefits to providing cancer patients with this type of information. Among them are: increased participation in the treatment decision process and increased satisfaction with the treatment choice; a sense of gained control and a resulting ability to better cope with the stress of the diagnosis; an increased ability to cope with treatment-related issues; and an increased amount of understanding of the disease and the issues that surround it among family members and other providers of support.

However, even though the need for such information is clear, it is believed that patients who have just received a diagnosis of prostate cancer frequently do not receive accurate, unbiased information about the potential benefits and the potential risks of

each treatment option before therapy is initiated.

This lack of information can diminish patients' quality of life and ability to cope with the disease. Baseline information must be obtained to determine whether, and to what extent, current patient education activities are meeting patients' needs for information about prostate cancer and the options for treatment.

Once that information is known, it can be used to develop and disseminate patient education materials that will help men newly diagnosed with prostate cancer join with their providers to make informed decisions about their preferred course of treatment and, thus, take an active role in managing their own health care.

What Needs to be Done

In order to determine the extent to which patients currently are educated about the potential benefits and potential risks associated with various treatments for prostate cancer, several challenges first must be overcome.

For instance, the target audience for both the survey of patient knowledge and any necessary educational intervention is men who have just been diagnosed with prostate cancer and who have yet to make a treatment decision. But, the need to protect patient confidentiality and the small window of time between diagnosis and treatment (two to eight weeks) make access to this group inherently difficult.

There are two main routes of access to these patients: 1) through their diagnosing physicians (urologists) and 2) through the hospital systems serving them.

Obviously, then, without the active endorsement and support of urologists, hospitals, participating institutions, and the community at large, it is unlikely that any patient educational intervention will be successful. In addition, without sustained efforts, educational interventions are not apt to be ongoing successes.

Therefore, the members of the Michigan Cancer Consortium Prostate Cancer Action Planning Group have devised a strategic action plan that will develop and implement a survey to assess the knowledge and impressions of men newly diagnosed with prostate cancer, then use the results of the survey to develop and disseminate educational materials for Michigan men who have been newly diagnosed with prostate cancer.

Specifically, members of the group have devised the following objectives to meet their goal of increasing men's knowledge and understanding of prostate cancer, as well as the treatment options, side effects, and quality of life issues associated with the disease.

***Objective #1*: Develop, distribute, and analyze a questionnaire targeting newly diagnosed patients with prostate cancer from diverse areas throughout Michigan on their knowledge about the topic of prostate cancer, treatment options, side effects, and quality of life issues.**

Prior to implementing this assessment survey, sanction for the project should be sought and obtained from both the American Urologic Association and the American Medical Association. Hospitals/health systems and urologists in Michigan should be contacted to obtain their commitment to circulate the survey to recently diagnosed prostate cancer patients.

Several focus groups should be convened, with members identified through prostate cancer support groups, to provide input on concerns of newly diagnosed prostate cancer patients who have not yet been treated for prostate cancer.

Separate focus groups should be formed to address the cultural needs of specific segments of the state's population, including African-American men and Hispanic men, as well as men living in both inner city and rural

areas. Spouses also should be encouraged to participate in the focus groups.

Based upon the information gained from the focus groups, the survey questionnaire should be developed and pilot-tested on a representative subset of prostate cancer patients, and revised as necessary. Once the survey design is complete, the questionnaire should be sent to the hospitals and urology practices that have agreed to participate in the study.

Objective #2: Based on knowledge gained from results of questionnaire, create and distribute an educational intervention to all prostate cancer patients who are newly diagnosed and have not yet made the treatment decision.

The educational intervention should focus on an overview of the disease of prostate cancer, treatment options, treatment side effects, and quality of life issues. It should be based upon the results of the survey and should consist of brochures, videos, and community-based educational programs. Other potential educational vehicles, such as web sites, hotlines, and audio tapes, also should be considered.

Whereas the survey of patients' knowledge of prostate cancer clearly will be limited by logistic considerations, the educational intervention should be available to all men in Michigan who have just been diagnosed with prostate cancer and should be disseminated to a broad constituency of men through hospital outpatient clinics, private physicians' offices, and prostate cancer support groups.

Efforts should be focused on reaching men who are from minority and/or underserved populations, men who are uninsured, men of varying educational and ethnic backgrounds, and men who live in rural parts of the state.

Pre- and post-test evaluations of the outcomes resulting from the educational intervention should be conducted.

Assuming the educational intervention is well-received, it should become part of an ongoing process of educating men and their families about prostate cancer and the range of issues associated with it.

Endnote:

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Clinical Cancer Research: Increasing the Number and Diversity of Participants

Goal: ***By 2005, double the number and increase the diversity of participants enrolled in clinical cancer research.***

Why This Goal Is Important

Major advancements in cancer prevention and clinical treatment invariably are the result of clinical research. Clinical trials provide the mechanism to transfer knowledge and innovations from the laboratory bench to the bedside, compare current treatment options, and promote excellence in the practice of oncology.

Although the benefits of clinical research have been documented and promoted for years, the participant enrollment statistics for these trials continue to be abysmally low. For instance, it is estimated that only 2 percent to 3 percent of cancer patients are recruited to participate in treatment clinical trials.

Physician biases may be the most important factor in determining whether a patient enters a clinical trial. Too often, the patient's medical treatment staff are unfamiliar with available clinical trials, unwilling to offer trials as perhaps the best treatment option for the patient, or unwilling to devote additional time to explaining the clinical research process.

Another major obstacle to recruitment is providers' fear of losing patients once they join a clinical trial. As a group, physicians must be better educated about trials and encouraged to support their patients' participation in them. Research indicates that a primary care provider's support for a trial may be essential in getting a patient's cooperation, especially in those instances when a patient seeks an objective opinion from someone they trust.

Eligible patients refuse to participate in trial studies for a number of reasons, including fear of toxicity; real or perceived personal cost; the time and effort involved in participating; fear of unpleasant side effects; not wanting to be a "guinea pig;" an unwillingness to relinquish control; and a concern that clinical investigators may show more allegiance to the trials than to the patients.

In addition, patients and their families typically do not understand the nature of clinical trials and the randomization process. We must address these concerns of eligible candidates and their family members if trial enrollment is to increase.

It is especially crucial that under-represented minority populations and the elderly participate in clinical trials so the safety and efficacy of new treatments can be assessed as they relate to these populations. However, recruitment of these individuals lags far behind that of the general population.

Minority patients not only share the same barriers as other reluctant patients, they also have additional social, cultural, and economic barriers to participation (e.g., widespread fear and mistrust of the medical care system, lack of access to health care in general, language barriers, lack of education, lack of transportation, lack of access to a telephone).

Not all physicians have access to clinical trials due to a number of barriers.

A significant number of physicians are not affiliated with a clinical trial group, a situation that often means they cannot access trials run by such a group. Many physicians cite bureaucratic or logistical concerns for

not placing patients in studies. Others cite excessive physician time requirements as an issue, as well as insufficient support for follow up and lack of adequate funding to cover the personnel and training costs of research nurses, data managers, and administrative staff.

Internal review board regulatory issues are necessary to ensure ongoing informed consent and safety.

However, lengthy, complex, intellectually challenging "informed consent" documents are considered a major obstacle in placing patients on clinical trials. Likewise, the detailed recitation of possible side effects without regard to the likelihood of that side effect actually occurring can be detrimental to true "informed consent."

It is estimated that perhaps as much as half the cost of performing a study can be traced to the need to develop an initial consent form and obtain approval of the amendments and early updates, as well as report the adverse drug reactions.

Although third-party payers routinely reimburse clinical trial patient care costs, the current "don't ask, don't tell" policy keeps physicians fearful of audits and patients concerned that suddenly none of their care will be covered.

While insurance companies acknowledge that participation in clinical trials is necessary and even can be a quality indicator, they have real concerns regarding incremental costs and lack of systems to track patients on studies. Managed care organizations may deny coverage for experimental treatments outright, or in the case of capitated contracts, may place the onus on the physician and health care system, making them decide between the relative benefits and the relative costs of promising, but expensive, new drugs.

What Needs to be Done

Despite efforts by the National Cancer Institute and national patient advocacy groups to increase awareness of clinical trials as possibly the best treatment option for a patient, the proportion of cancer patients who participate in trials still remains extremely low.

To increase participation in clinical studies, we must obtain the active endorsement of community medical providers, the encouragement of local thought leaders, and the commitment of health care payers and their accounts.

To achieve these needs, the Michigan Cancer Consortium's Clinical Trials Action Planning Group has developed a strategic action plan focused on six major areas that influence participation in clinical trials:

1) physician/provider bias;
2) patient/public attitudes;
3) minority issues;
4) trial design;
5) access to trials; and
6) coverage issues.

The plan includes strategies and initiatives designed to encourage partnerships among all segments of the community that have a vested interest in better cancer outcomes. Specifically, it includes the following objectives.

Objective #1: Establish a mechanism to measure cancer clinical trial participation.

A survey tailored to reflect enrollment of Michigan population groups and designed to encompass all treatment, supportive care, and prevention trials currently active in our state should be developed and implemented.

The results should be used to establish a baseline of current clinical trial participation and should serve as a success indicator measurement for increasing enrollment among various populations.

Objective #2: Increase enrollment in clinical trials by reducing physician/ provider bias.

To insure that cancer patients in all Michigan communities have access to clinical

trials, physicians must be kept appraised of current research opportunities, convinced of the value of participation, and encouraged to work toward increasing clinical trial enrollment. Therefore, implementers should develop and implement an education effort targeted at all providers that treat cancer patients, including medical students, residents, fellows, and attending physicians.

All researchers should be encouraged to increase feedback and follow-up reporting to referring physicians (e.g., it is recommended that both cumulative results of studies and reports on individual patients be provided to the referring physician).

Objective #3: Increase enrollment in clinical trials by influencing patient attitudes.

Volunteers throughout the state should be trained in the use of the National Cancer Institute's cancer clinical trials education program initiative called "Train the Trainer," and should be organized to provide a consistent, well-supported program to any group requesting it.

Additional resources should be developed to emphasize the need for clinical research, address the public's concerns and misinformation, and encourage enrollment in studies. These could include a patient web site that offers a listing of Michigan physicians participating in clinical trials, lists of available studies, general information for those considering participation, and links to related clinical trial web sites, and a multi-media advertising campaign that encourages participation in clinical trials.

Interested persons and organizations should be encouraged to work with advocacy group "hotlines" to ensure information about all Michigan clinical trials is up-to-date and accurate.

Objective #4: Collaborate with minority community agencies and leaders to increase the diversity of patients enrolled in clinical trials.

In recognition of the fact that minority physicians often serve, and are most trusted by, minority populations, implementers should work with minority health care providers to increase their participation in trial design issues, patient recruitment, and follow up.

In addition, partnerships should be developed with social agencies working with minorities as a way of reaching targeted populations by learning how to overcome language, cultural, and socio-economic barriers.

Objective #5: Increase physician cooperation and participant enrollment by disseminating information on trial design improvement.

In part, community physicians have been reluctant to commit to trial participation because of the demands on their limited time and resources. National efforts and achievements should be promoted at the local level to recruit community physician involvement.

The pharmaceutical industry should be encouraged to provide resources that can be used to support innovative programs to achieve this objective.

Objective #6: Increase participant enrollment in trials by expanding access and infrastructure support to community physicians.

Placing clinical trials in patients' communities actively enhances patient care by providing the highest level of therapy, as well as advancing the field of hematology and oncology. Implementers should promote the development of research networks for community practitioners. A web site should be developed and maintained to help Michigan physicians identify local trials and access further information about them, including contact names and telephone numbers.

<u>Objective #7</u>: Increase participation in clinical trials by resolving insurance coverage issues.

Reimbursement is the linchpin in successful clinical trial recruitment efforts.

Existing models and initiatives should be utilized to secure full coverage of routine patient care costs for patients enrolled in clinical trials. Efforts to make clinical trial participation a cancer program quality indicator should be promoted. Payers should be informed about the fact that clinical trial participation is a continuous quality improvement initiative.

A Clinical Trials Summit should be convened with major players from the provider, payer, and patient advocacy communities, not to pursue insurance mandates, but to identify effective alternatives.

Partnerships should be established with state agencies to form a working group to improve clinical outcomes for oncology.

A pilot program should be tested with insurers and major employers to tie clinical trials to guidelines for best care, including access to clinical trials for any patients who meet eligibility criteria.

A collaborative workgroup consisting of representatives from Michigan academic medical centers, health care payers, and major employers should be convened to review and report on the utilization of clinical trial protocols and guidelines in the community setting.

Statewide Clinical and Cost Database: Establishing a Database for Breast, Cervical, Colorectal, Lung, and Prostate Cancers

Goal: ***By 2005, develop the linked economic and clinical database infrastructure necessary to support data-driven decisions for control of breast, cervical, colorectal, lung, and prostate cancers within the state of Michigan.***

Why This Goal Is Important

In order to distribute limited cancer control resources in the most efficient manner, we must first understand the relative costs and health outcomes for treatment, prevention, and screening.

Although many of the resources allocated to cancer control and health outcomes in Michigan are tracked, few are located within one database. There currently is no single system that can provide the necessary information about risk factors, preventive measures, and treatments of cancer to allow policy makers to consider both cost and outcomes.

Thus, when policy makers want to understand the scope and range of issues surrounding a cancer intervention, they typically must perform a specialized survey that will provide them with enough data to evaluate options and perform an economic analysis.

This limitation inherently is time-consuming and reduces the potential for accurate information. It therefore limits the ability of health care policy makers and providers to make decisions that take into account both the cost and outcomes of various treatments, prevention strategies, and screening methods.

Like policy makers, cancer control practitioners and health systems must understand the clinical and economic implications of the decisions they make in order to maximize the benefits to their patients.

The fact that there currently is no single, centralized statewide database that contains both economic and clinical data for breast, cervical, colorectal, lung, and prostate cancers creates a gap that is not easily filled. It means that important information, such as the cost of serving uninsured individuals and the economic impact of failing to provide comprehensive cancer care, is not available to practitioners, health systems, policy makers, and others who may need it.

These issues may be addressed by the formation of a centralized statewide database that would provide accurate information in a concise manner and give researchers and policy makers the tools they need to display clearly to providers and to the public the trends affecting cancer treatment. Such a database also would provide policy makers with the tools they need to advocate for policy changes that address those new trends by enabling them to more clearly articulate the reasoning behind the recommended policy changes, as well as the benefits of implementing those changes. This could include such vital issues as improved access to treatment and greater awareness of risk factors.

A centralized, statewide economic and clinical cancer database would enable investigators to explore the cost of cancer patient care by relating cost of care to stage at diagnosis and treatment outcome. Likewise, such a database would allow

researchers to study the inter-association between socioeconomic data, health status, and health care cost, including how they relate to incidence and stage at diagnosis.

Such a database also would make a host of other study topics available, all of which would result ultimately in increased knowledge about cancer-related prevention, screening, and treatment methods and a higher level of patient care.

What Needs to be Done

A centralized, statewide economic and clinical cancer database for the state of Michigan should be established and maintained to track cost-effectiveness data on cancer treatment, interventions, and risk factors. The database should be accessible to all health care researchers, policy makers, and providers in the state to enable them to evaluate outcomes and compare them with costs, if desired.

To accomplish this, pilot projects must first be developed and run to determine whether it is feasible to select per-patient charge data from one or more payer databases and cross-link them with clinical data from another to create a new database containing both economic and clinical data related to cancer.

If it can be established that it is feasible, useful, and affordable to do so, a standing, comprehensive statewide economic and clinical database for breast, cervical, colorectal, lung, and prostate cancers should be created in Michigan.

Members of the Michigan Cancer Consortium's Economic/Clinical Database Action Planning Group have developed a strategic action plan to address the questions surrounding the establishment of such a database within the state and to establish a centralized database for breast, cervical, colorectal, lung, and prostate cancer data if it is appropriate to do so. Specifically, their plan includes the following objectives.

To Determine the Feasibility, Usefulness, and Affordability of a Centralized Database:

Objective #1: Implement and evaluate a pilot demonstration to determine the feasibility, costs, and benefits of merging cancer-related cost and clinical elements from multiple databases.

A pilot demonstration using 1994-1996 breast cancer data from southeastern Michigan should be designed and tested to determine whether per-patient charge data (cancer care only) from Blue Cross Blue Shield of Michigan (BCBSM) can be selected and cross-linked successfully with breast cancer clinical data from the metro-Detroit Surveillance, Epidemiology, and End Results database to produce a single, useful breast cancer charge and outcome database.

Prior to selecting and cross-linking the data, a collaborative workgroup should be convened to:

1) clarify the purposes for the database;
2) determine how to summarize the cancer data for reporting purposes; and
3) determine how to match breast cancer charge data with the corresponding clinical data.

The results of the pilot demonstration should be evaluated and consensus should be reached regarding the feasibility of expanding the database test.

Objective #2: Implement and evaluate an expanded pilot demonstration to match statewide charge data (both cancer and non-cancer care) from all Blue Cross plans and the Michigan Medicaid Program to clinical data from the Michigan Cancer Registry.

A pilot demonstration should be designed and tested to determine whether 1994-1996 statewide per-patient charge data (cancer and non-cancer care) from traditional, managed care, and point-of-service Blue Cross programs and the Michigan Medicaid

Program (including Qualified Health Plans) can be selected and cross-linked successfully with corresponding clinical data from the Michigan Cancer Registry to produce a single, useful economic and clinical database for breast, cervical, colorectal, lung, and prostate cancers. The feasibility, costs, and benefits of the expanded demonstration database test should be evaluated and consensus should be reached regarding the future expansion of the project.

Objective #3: Implement and evaluate a statewide field test that adds charge data from Medicare, other managed care plans, self-insured plans, and other major health care payers in Michigan to the statewide cancer database demonstration process.

Agreements should be obtained from Medicare and as many other major health care payers in the state as possible to participate in a statewide cancer database field test.

A pilot field test should be designed and implemented to determine whether 1994-1996 statewide charge data (cancer and non-cancer care) from all previous demonstration participants, as well as from Medicare and many managed care plans, self-insured plans, and other major health care payers in Michigan can be selected and cross-linked with corresponding clinical data from the Michigan Cancer Registry to produce a single, comprehensive statewide economic and clinical database for breast, cervical, colorectal, lung, and prostate cancers.

Prior to selecting and cross-linking the data, a collaborative stakeholder workgroup should be convened to:

1) identify a data reporting format and process that will accommodate the needs of all participants; and
2) clarify the procedures necessary to match and summarize charge and clinical data from all the databases involved.

The results of the field test should be evaluated and consensus should be reached regarding the feasibility, costs, and benefits of establishing and maintaining a standing, comprehensive statewide economic and clinical cancer database.

To Establish and Maintain a Standing, Centralized Cancer Database:

Objective #1: If determined to be feasible, useful, and affordable, implement a standing, comprehensive, statewide economic and clinical database for breast, cervical, colorectal, lung, and prostate cancers in Michigan.

A collaborative workgroup of stakeholders should be convened to:

1) identify a data reporting format and process that will accommodate the needs of all participants; and
2) clarify the procedures necessary to match and summarize charge and clinical data from all the databases involved.

A site that is agreeable to all stakeholders should be chosen to house the database. The necessary funding for building the database should be secured, and the necessary infrastructure for establishing and maintaining the database should be developed.

Commitments should be secured from the Michigan Department of Community Health and the Michigan Medicaid Program (including Qualified Health Plans), Medicare, and as many other major health care payers in the state as possible to participate voluntarily in the database on an ongoing basis.

Statewide per-patient breast, cervical, colorectal, lung, and prostate charge data (cancer and non-cancer care; as many years as possible) should be obtained from all participating payers and cross-linked to corresponding clinical data (cancer and non-cancer care) from the Michigan Cancer

Registry to form one centralized database.

An oversight committee of health care providers, researchers, public health representatives, and payers should be convened to:

1) maintain the efficacy of the database as a tool to support data-driven decisions for the control of breast, cervical, colorectal, lung, and prostate cancers within Michigan and
2) determine the need, feasibility, and cost of adding other elements to the database, such as environmental and social demographic factors.

The availability of the database should be promoted to potential users as appropriate.

End-of-Life Care: Increasing the Timeliness of Referrals for Cancer Patients

Goal: ***By 2005, increase the timeliness of referrals to end-of-life care for breast, cervical, colorectal, lung, and prostate cancer patients.***

Why This Goal Is Important

It is beyond question that end-of-life services for cancer patients with terminal diagnoses are underutilized. When used, these services often are begun long after they could have been, to the detriment of effective and compassionate care.

The benefits of comprehensive end-of-life care, which addresses the management of pain and other physical symptoms, as well as a range of emotional and spiritual support services for patients and their families, accrue over time. Yet, by definition, time for these individuals is short. Therefore, timeliness of referral is crucially important.

Even a 100 percent referral rate to end-of-life care would be deemed a failure if the brief time between referral and death did not allow medical, psychological and spiritual care professionals to help patients and families with the complicated process of dying.

However, up to 40 percent of Michigan hospice patients are in hospice for less than two weeks, which leaves little time for the benefits of multi-disciplinary end-of-life care to accrue. In fact, although total numbers of users have increased, the length-of-stay figures have declined.

This may be the clearest marker that many, if not most, referrals to end-of life care are not occurring in a timely manner.

Underlying the lack of knowledge, poor communication, and misperceptions that exist about hospice and palliative care is the way our society talks (or doesn't talk) about death. Individuals who want to address the issue of death lack the vocabulary to begin a discussion.

Physicians, the most likely gatekeepers for timely referrals, are trained to believe that disease and death are the enemy, and often reject models of care that, in their eyes, concede defeat.

Even when physicians are prepared to face an inevitable death, their ability to provide the care that is needed often is hindered by such factors as a lack of training in palliative medicine, particularly pain management, and a lack of knowledge about hospice care; concern about prescribing opioids; and lack of a clear understanding of their role in the team model of hospice care.

Discharge planners and case managers often do not bring up the subject until they have been given clear direction by the medical team to do so. Families and even patients themselves may be slow to accept a palliative care model that no longer looks toward a cure.

The fact that our culture has largely put the topic of death "off limits" means that these decisions may be reached in silence.

Who's Affected

National statistics kept by the National Hospice Organization indicate that only 25 percent to 30 percent of cancer patients use hospice.

Data from Michigan are constructed in a way that makes such a calculation difficult for the state alone, but it is reasonable to assume that Michigan hospices, the primary providers of end-of-life care in the state, are not being used to their full advantage.

Even with the continued expansion of hospice and other end-of-life services, a majority of the users of these services tend to

be white, middle-class, and suburban.

Those who provide end-of-life care need to develop greater sensitivity to cultural mores, inhibitions, fears, and other factors that may present barriers to utilization of end-of-life services among distinct subgroups in Michigan.

These subgroups include minorities, inner city and rural residents, and the economically disadvantaged, categories that may well overlap. Individuals who are homeless, who live alone, and who live in unsafe home environments also are underserved.

What Needs to be Done

Serious gaps in the training of health care professionals, a lack of effective public education, the inadvertent consequences of public policy, and insufficient attention to the needs of diverse populations all can act as barriers to timely referrals to end-of-life care. To compound the problem, data that give a clear picture of referral patterns—which would detail both the extent of the problem and the effects of interventions—are incomplete.

The Michigan Cancer Consortium's Action Planning Group on Timely Referrals to End-of-Life Care has devised a strategic plan to address these factors. The plan includes activities in the areas of data collection and benchmarking; referral guidelines; and barriers internal to the hospice industry.

The group has taken care to integrate minority concerns fully into the plan's strategies and action steps. Specifically, their plan addresses the following objectives.

Objectives Related to Hospice Care:

Objective #1: Establish benchmarking statistics through an initial data collection project, with subsequent annual research that will generate baseline and ongoing data to measure improvement in referral patterns to hospice care for patients with breast, cervical, colorectal, lung, or prostate cancer.

Objective #2: Establish guidelines for referral to hospice care for patients with breast, cervical, colorectal, lung, and prostate cancer diagnoses. Work with the National Hospice Organization to evaluate and implement cancer referral guidelines to assist referral sources in making timely referrals, and include the development of guidelines on the use of chemotherapy and radiation therapy. Communicate the proper use of those guidelines to referral sources.

Implementers should work with the National Hospice Organization to identify pilot test sites in Michigan to test guidelines for referral of patients with cancer diagnoses to hospice care.

Guidelines should be established that address the economic, cultural, and ethnic diversity of Michigan residents, and the finalized guidelines should be communicated to all hospice programs in the state. The finalized guidelines (and proper use of those guidelines) should be communicated to all referral sources, including physicians, discharge planners, insurance and related firms, home health agencies, and others.

Objective #3: Clearly identify internal barriers to hospice referral. Use the results of barriers research to improve the ability of hospice management to identify and work with referral sources.

A select sample of hospice executives from a variety of hospice programs should be surveyed to identify the most critical internal barriers to timely referrals. Concurrently, research should be conducted among discharge planners and other referral sources to identify hospice-specific barriers to referral.

Once barriers have been identified, educational materials and a coordinated information campaign should be developed

to assist hospice programs in referral education activity and open regular channels of communication with all appropriate referral sources. Referral sources that should receive informational and educational materials should be identified.

Objectives Related to Professional Education:

Objective #1: Improve formal professional education on end-of-life issues and practice.

An extensive review of what end-of-life education already is taking place in Michigan's medical schools (including in primary care residency programs and oncology fellowships) should be conducted. Reviews also should be conducted in Michigan's nursing schools, and in Michigan schools that teach counseling and pastoral care.

The development of a palliative care and end-of-life curricula, including hospice experience, should be supported in medical, nursing, counseling, and pastoral care schools in the state.

Objective #2: Improve continuing education for practicing professionals on end-of-life issues and practice.

Implementers should use available continuing education avenues to educate physicians, nurses, and psychological and spiritual counselors about appropriate end-of-life issues.

Health care providers should receive education regarding pain and symptom management; available end-of-life services in their communities; billing/coding for services commonly involved in care for the dying (e.g., home visits, case management); liability and regulatory issues surrounding care for the dying (e.g., the Michigan Dignified Death Act and the Medicare Hospice Benefit); the palliative care model multi-disciplinary health care team; the role of the caregiver and family needs in end-of-life bereavement; and their role in hospice and palliative care.

Psychological and spiritual counselors should be educated about available end-of-life services in their communities and the palliative care model multi-disciplinary health care team.

Continuing education efforts should support the development of physician, nursing, and psychological/spiritual professional role models whose palliative care practice for the patient, caregiver, and other family members, can act as examples for others to follow.

Inter-disciplinary conferences should be held for all targeted professionals. A conference for physicians, nurses, social workers, mental health professionals, and clergy ideally would model the team approach to end-of-life care and provide opportunities to share resources and perspectives and to learn collaboratively.

Objective Related to Public Education:

Objective #1: Influence consumer demand for end-of-life options, and identify key means for communication and education about end-of-life care in diverse settings.

Patients and families should be interviewed about their hospice experience and focus groups should be held with families who have previously used hospice services to determine what would have made them seek hospice sooner, what barriers they faced, and what information they wanted to know about hospice services and at what time they wanted to know it.

The results of the interviews should be used to develop resources about end-of-life choices for the general public in a variety of formats and settings.

Objectives Related to Public Policy:

Objective #1: Review current initiatives in end-of-life care sponsored by statewide organizations and coalitions in Michigan, as well as initiatives in other states, and build alliances with groups that can serve as conduits for proposed policy initiatives.

Objective #2: Review existing state laws and their enforcement to assess possible barriers to timely referral to end-of-life services, and propose changes.

Prescribers should be surveyed to determine the impact of the Michigan Official Prescription Program (MOPP). The report on the MOPP conducted by the Department of Consumer and Industry Services in 1997 should be analyzed.

Alliances should be formed with, and support should be lent to, groups working to address any identified barriers posed by the MOPP.

Physicians should be surveyed to gauge their understanding of the Death with Dignity Act.

A managed care plan willing to implement pilot measurement of physician compliance with Death with Dignity Act requirements should be identified and worked with to implement improvement efforts. Results should be shared through the Michigan Association of Health Plans and other organizations.

Objective #3: Review reimbursement for hospice benefits and influence changes. Ensure that Michigan interests are represented at the federal policymaking level.

Individuals and institutions affected by the Medicare Hospice Benefit should be surveyed to document funding and programmatic issues and needed reforms, and Medicare changes that would resolve these problems should be supported.

Reimbursement plans that differ from Medicare should be examined, and affected individuals and institutions should be surveyed to document funding and programmatic issues and needed reforms; results should be compared with the Medicare survey.

Organizations representing interested parties should be encouraged to formulate consensus solutions and coordinate with national organizations of like mind.

Objective #4: Consider adoption of palliative care performance measures, such as the Palliative Care Index used in the Department of Veterans Affairs.

Existing palliative care performance measures should be reviewed to determine if such measures should be implemented in some form on a statewide basis.

Objectives Related to Minority and Culturally Diverse Populations:

Objective #1: Develop and test hospice outreach to minority, lower-income, rural, and other underserved groups.

The extent of the problem, its sources, and possible solutions should be assessed.

As part of hospice data collection, researchers should measure utilization by the named population subgroups against state cancer death statistics, and collect and assess length of stay data for various groups.

Hospice educational programs should be developed for population subgroups and service providers. Ways to open regular channels of communication between hospice and targeted subgroups should be investigated and implemented.

Objective #2: Address special issues of minority and underserved populations during formal and continuing professional education.

Educators should include issues relating to the special needs and concerns of minority populations in formal health care professional courses dealing with the

relationship between the professional and the patient.

In using role modeling as a teaching tool, practitioners who will serve as role models from a variety of racial, ethnic and religious groups, and from a variety of practice settings, should be selected.

Topics related to minority and underserved groups should be included on an ongoing basis as part of end-of-life conferences for practicing professionals.

<u>Objective #3</u>: Target public education messages to specific underserved populations.

Research should be conducted into models that have been successful in terms of reaching minority and underserved Michigan residents in other health-related matters. Educational interventions should be examined to determine if they can be made to include, or separately tailored for, specific populations.

Health care professionals and others from minority racial, religious, ethnic, and geographical groups should be identified to participate in working groups and educational programs. Working groups and task forces should include representatives from Michigan organizations, both medical and non-medical, that have been established to address minority issues.

<u>Objective #4</u>: Review reimbursement and issues of access to care that may affect specific populations in particular ways, and propose policy changes.

Data on utilization of end-of-life services by minority groups and other historically underserved populations should be gathered and patterns of utilization should be analyzed to identify barriers to better access.

Standardized Lexicons and Reporting Formats for Cancer: Developing Them and Promoting Their Use

Goal: ***By 2005, develop and disseminate standardized pathology protocols and reporting formats for examination of cancerous tissue specimens and determine the need for similar surgical reporting formats that include data important in making breast, cervical, colorectal, lung, and prostate cancer treatment and prognostic decisions.***

Why This Goal Is Important

While evidence exists that screening and early detection can reduce mortality from breast, cervical and colorectal cancer, it is a fact that mortality from these cancers can be reduced only if early detection is followed by appropriate treatment.

Although choices among treatment alternatives may be available, the decision about which alternative would be most appropriate for an individual depends upon many factors, including the particular characteristics of the cancerous lesion itself.

In fact, cancer treatment services are best provided by a team of providers, all of whom must accurately communicate key data to one another so all members of the team have the information they need to evaluate the situation, determine the most effective treatment regimen, and establish a realistic prognosis for the patient.

Pathologists, radiologists, and surgeons often use a wide variety of narrative descriptions to outline a patient's diagnosis and potential course of cancer treatment.

A lack of consistency in these descriptions can create confusion in the minds of other care providers who review such descriptions to develop an oncology management plan for an individual patient.

For instance, oncologists use two basic sets of information to make decisions about which treatment to select as the most effective for an individual patient:

1) an analysis of the report about the characteristics of the cancerous lesion from the pathologist who examined the anatomical specimen to make the diagnosis, and
2) information contained in the operative report from the surgeon who performed the initial biopsy or excision.

Inconsistencies in the way these findings are reported may result in an oncologist selecting less-than-optimal treatment options, as well as communicating misleading information to the patients and their families.

Health care policy makers and analysts also need consistent and accurate data from surgical and pathology reports to determine the cost-effectiveness of various health care measures, including screening strategies and treatment modalities.

Because oncology teams need the information from pathology and operative reports to plan and monitor outcomes of treatment, it is imperative that the reports not only contain the information deemed necessary for decision-making, but that the terminology used be universally understood by all providers.

Yet, experts say that both the data reported and the reporting format and terminology used by pathologists and

surgeons often differ by geographic area, by health care system, and even by individual provider within the same practice setting.

Members of the Michigan Cancer Consortium Standardized Lexicon Action Group believe a plan should be implemented to develop standardized pathology practice protocols and standardized pathology reporting formats.

Much work already has been done in this area on the national level, and some professional organizations already have published their own standardized pathology practice protocols. However, these recommended standardized formats are not used universally by members of the pathology community.

It is apparent that surgeons, pathologists, diagnostic radiologists, and oncologists all must reach consensus about their information needs and how those information needs should be reflected in the final products from each practitioner.

If standard formats or lexicons can be created and used universally, it stands to reason that diagnostic and treatment decisions will be improved measurably.

What Needs to be Done

Based upon a limited review of the literature regarding the desirability and efficacy of using standardized lexicons and reporting formats for pathologists and surgeons, and the methodology for development of such, members of the Standardized Lexicon Action Planning Group have developed a strategic action plan to address:

1) the development of standardized practice protocols for pathologists;
2) the need to educate medical professionals, health care policy analysts, and tumor registrars about the standardized pathology protocols and how to use them;
3) the dissemination of the standardized pathology protocols and the integration of them into practice; and
4) determination of the feasibility of developing a standardized format for surgical reports.

The plan includes opportunities for a wide array of professional organizations, state agencies, insurers, and other interested parties to form collaborative partnerships and work on strategies that will result in the realization of the overall goal of enhanced communication among cancer-care providers and decision makers. Specifically, members of the group have devised the following objectives.

To Develop Standardized Pathology Practice Protocols:

***Objective #1*: By 2002, the medical community, tumor registrars, and health care policymakers and economists will reach consensus on a standardized pathology protocol for examination and reporting of cancers of the breast, cervix, colon and rectum, lung, and prostate gland.**

Consensus must be reached about the elements that should be included in a standardized pathology protocol that can be used when examining specimens removed from patients with cancer of the breast, cervix, colon and rectum, lung, or prostate gland.

Michigan pathologists, surgeons, medical oncologists, and radiation oncologists must reach consensus on a standardized protocol that will ensure that all the information necessary to make diagnostic, treatment, or prognostic decisions is gathered. Likewise, Michigan tumor registrars must reach consensus on a standardized protocol that contains all the pathology data elements required by the state and national cancer registries.

In addition, Michigan health care policy and economic groups must reach consensus on a standardized pathology protocol that

will report enough data about cancers of the breast, cervix, colon and rectum, lung, and prostate gland to enable them to make accurate outcome projections and analyses.

Once these groups arrive at consensus, their recommendations can be incorporated into new standardized pathology practice protocols for examination and reporting of cancerous breast, cervix, colon and rectum, lung, and prostate gland tissue specimens.

To Educate Professionals About the Protocols:

Objective #1: ***By 2003, Michigan pathologists, surgeons, medical oncologists, and radiation oncologists will understand the benefit of, and the methodology for, the consensus practice protocols for examination and reporting of specimens removed from patients with cancer of the breast, cervix, colon and rectum, lung, or prostate gland.***

It is recommended that a panel of providers, health care policy analysts, and tumor registrars use the final consensus practice protocols to develop checklists for reporting breast, cervix, colon and rectum, lung, and prostate gland tissue examination results that can be used as summaries of the traditional narrative descriptive pathology reports. Once the checklists are developed, members of the medical community, health care policy analysts, and tumor registrars all must reach consensus on the elements and use of the checklists.

To Disseminate the Protocols and Integrate Them Into Practice:

Objective #1: ***By 2005, 50 percent of Michigan anatomical pathologists will utilize the consensus practice protocols and standardized reporting formats for examination and reporting of cancerous specimens from the breast, cervix, colon and rectum, lung, and prostate gland.***

The consensus practice protocols and checklist reporting formats should be disseminated to all practicing pathologists, surgeons, medical oncologists, and radiation oncologists in Michigan.

A team of pathologists, surgeons, medical oncologists, and radiation oncologists should be assembled to serve as peer educators and consultants to colleagues integrating the use of the new protocols and checklists into their practices.

Michigan anatomical pathologists should adopt and utilize the protocols for examination of cancerous breast, cervix, colon and rectum, lung, and prostate gland specimens, and they should use the checklists for reporting on the examinations of those specimens.

Michigan surgeons, medical oncologists, and radiation oncologists should request reports on such tissue examinations in the standardized checklist formats.

Tumor registrars should use the checklist reporting formats when filing reports of breast, cervix, colon and rectum, lung, and prostate gland cancers with state and national registries, thus ensuring that the registries receive completed reports containing all the required data elements.

To Determine the Feasibility of Developing a Standardized Format for Surgical Reports:

Objective #1: ***By 2004, surgeons, oncologists, tumor registrars, and policy analysts will reach consensus about the necessity of developing a standardized format for operative reports.***

A panel of surgeons, medical oncologists, radiation oncologists, health care policy analysts, and tumor registrars should be assembled to analyze operative reports and recommend a list of data elements that are essential for making treatment decisions and, thus, should be included in all surgical records.

Panel members then should analyze a random sample of operative reports describing breast, cervix, colon and rectum, lung, and prostate gland surgical procedures and determine whether the majority contain the elements deemed essential for making treatment and policy decisions and also meet the data requirements of the state and national tumor registries.

Once the analysis is completed, the panel should develop recommendations concerning the necessity of developing a standardized reporting format for surgical procedures of the breast, cervix, colon and rectum, lung, and prostate gland. The recommendations should be forwarded to the Michigan Cancer Consortium for consideration.

Appendix A:

Contributors to Michigan Cancer Consortium Initiative Strategic Plan for Implementation

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Charles Agerstrand
Michigan Education Association-Retirees

Connie Alfaro, R.N., M.P.H., M.S.
Division of Community Services
Michigan Department of Community Health
Representing: National Association of Hispanic Nurses, Michigan Chapter

Kathleen Altman, M.Ed.
Health Educator
Oakland County Health Division

Keith Ammon, M.A.
4-H Youth Programs
Michigan State University

Marilyn L. Anderson, M.S.N., R.N., C.T.A.C.-A.C.P.
Director, Behavioral Health Services
Holland Community Hospital

Janice Bach, M.S.
Coordinator, Hereditary Disorders Program
Michigan Department of Community Health

Irene Baker, R.N., M.S.N.
Women's Healthcare, Inc.
Representing: Michigan Nurses Association

Denise Ballard
Outreach Program Manager, NCI's Cancer Information Service
Barbara Ann Karmanos Cancer Institute

Kay Batterson
Division Sales Manager
SmithKline Beecham Consumer Healthcare

Marcia Baum, B.A.
Director, Community Outreach
Barbara Ann Karmanos Cancer Institute

Margaret Beall, E.M.T., M.P.H.
Michigan Public Health Institute

John K. Beasley, M.A.
Manager, Tobacco Section
Michigan Department of Community Health

Shirley Bentsen
Director of Training, Office of Services to the Aging
Michigan Department of Community Health

James Bergman, J.D.
Co-Director
Center for Social Gerontology

Lisa Berry-Bobovski
Assistant Director, Community Outreach
Barbara Ann Karmanos Cancer Institute

Julie Berson, M.P.H.
Recruiter/Trainer, Hazards of Tobacco Program
Barbara Ann Karmanos Cancer Institute

Mark J. Bertler, B.A., C.A.E.
Executive Director
Michigan Association for Local Public Health

Deanna A. Beyer, R.N., M.S.N.
Nurse Manager
University of Michigan

Vence Bonham, J.D.
Associate Professor of Medicine
Michigan State University
Representing: Michigan Breast Cancer Advisory Committee

Margie Bonner
Community Health Specialist
American Cancer Society, Great Lakes Division, Inc.

Aurea Booncharoen, B.S.N., M.A.
Division of Family and Community Health
Michigan Department of Community Health

Cathy J. Bradley, Ph.D.
Assistant Professor of Medicine
Cancer Center at Michigan State University

Sue Brennan, R.N.
Clinical Nurse Specialist
Ingham Regional Medical Center
Representing: Michigan Nurses Association

Peggy Brey, M.S.W., A.C.S.W.
Project Manager
Michigan Peer Review Organization

Leslie J. Bricker, M.D.
Medical Director
Hospices of Henry Ford Health System

Patrick Bridge, Ph.D.
Assistant Professor, Department of Family Medicine
Wayne State University

Brian Broderick, J.D.
Associate for Public Policy
Michigan Catholic Conference

Donald G. Bronn, M.D., Ph.D.
Medical Director
Michigan Institute for Radiation Oncology

Patricia Brookover, M.P.H., R.D.
Cancer Prevention and Control Section
Michigan Department of Community Health

Dorothy Brown, R.N.
Representing: Michigan Black Nurses Association

Robert C. Burack, M.D., M.P.H.
Professor of Medicine
Wayne State University

Gail Burke
Michigan Public Health Institute

Carol Callaghan, M.P.H.
Manager, Cancer Prevention and Control Section
Michigan Department of Community Health

Jim Camburn
Chief, Radiation Safety Section
Michigan Department of Consumer and Industry Services

Karen Carroll, M.S.W.
Training and Special Projects Analyst, Office of Services to the Aging
Michigan Department of Community Health

Jean Chabut, R.N., M.P.H.
Director, Division of Chronic Disease and Injury Control
Michigan Department of Community Health

Alfred E. Chang, M.D.
Professor of Surgery
University of Michigan Health System
Representing: American College of Surgeons, Michigan Chapter

Robert Chapman, M.D.
Division Head, Hematology/Oncology
Josephine Ford Cancer Center
Henry Ford Health System

Lisa Choate, M.S.
Senior Director, Prevention & Healthcare Programs
American Heart Association

Mary Ciotti, M.D., F.A.C.O.G.
Associate Professor, Department of Obstetrics & Gynecology
Michigan State University
Representing: American Cancer Society, Great Lakes Division, Inc.

Roxanne Clark, M.P.A., F.A.A.M.A.
Corporate Director, Cancer Care Services
McLaren Regional Cancer Center
Representing: Michigan Health and Hospital Association

Rabbi Philip Cohen, Ph.D.
Director, Hillel Student Center
Michigan State University

Mary Conklin, R.N., M.S.
Program Development Section, Division of Family & Community Health
Michigan Department of Community Health

Carla A. Cook, M.D.
Vice Chair, Radiation Oncology
William Beaumont Hospital
Representing: Michigan Radiological Society

Glenn Copeland, M.B.A.
Manager, Vital Records and Health Data Development
Michigan Department of Community Health

Sharon Daniels, R.N., M.S.A.
Administrator
Heartland Hospice
Representing: Michigan Hospice and Palliative Care Organization

Ronald Davis, M.D.
Director, Center for Health Promotion
Henry Ford Health System
Representing: Health Alliance Plan

Howard A. Dean, D.O.
Professor, Internal Medicine/Gastroenterology
Department of Internal Medicine
Michigan State University-College of Osteopathic Medicine

Peter DeGuire, M.P.H.
Vital Records and Health Data Development
Michigan Department of Community Health

Ruth Dein, R.N., B.S.N., O.C.N.
Oncology Nurse Educator, Rose Cancer Center
William Beaumont Hospital

Raymond Y. Demers, M.D., M.P.H.
Director, Josephine Ford Cancer Center
Henry Ford Health System

Karen Denolf, R.N., B.S.N., O.C.N.
Oncology Nurse Specialist
Munson Medical Center
Representing: Oncology Nursing Society, Traverse Bay Region

Gunter Deppe, M.D.
Director, Division of Gynecologic Oncology
Hutzel Hospital/Detroit Medical Center
Representing: Barbara Ann Karmanos Cancer Institute

Heather Dickson, M.D.
Deighton Family Practice Center
Representing: Michigan Academy of Family Physicians

Debra Dillingham
Cancer Control Program Manager
American Cancer Society, Great Lakes Division, Inc.

Donald G. Diskey, M.A.
Project Coordinator
Ingham County Health Department

Robert Dock, D.O.
Private Practice
Representing: Michigan Osteopathic Association

Dennis Dodson, M.S.
Vital Records and Health Data Development
Michigan Department of Community Health

Dan Dolanski, D.O.
Bureau of Epidemiology
Michigan Department of Community Health

Gordon Downey, M.D.
Gynecologic Oncologist
Representing: Michigan State Medical Society

Randy Drager
Representing: Hospice of Michigan

Susan Dusseau, M.A.
Executive Director
Midland Community Cancer Services
Representing: Michigan Colorectal Cancer Advisory Committee

John C. Eggenberger, M.D.
Division Head, Division of Colon and Rectal Surgery
Henry Ford Health System

Debera Eggleston, M.D.
Medical Services Administration
Michigan Department of Community Health

John Escott, M.D.
Department of Family Practice
Providence Hospital
Representing: Michigan Academy of Family Physicians

Jodie Faber, B.S., R.S.W., C.T.A.C.-A.C.P.
Social Worker
United Memorial Hospital

Joan M. Faulstick, M.A., N.C.C., R.N.
Tobacco Cessation Coordinator
W.A. Foote Memorial Hospital

Mary Dozzi Finkelstein, B.A., M.A.
SAFE Counselor
Waterford Schools

John W. Finn, M.D.
Executive Medical Director
Hospice of Michigan

Ruth Ann Foiles, R.D.
Representing: Michigan Dietetic Association

Jeffrey David Forman, M.D.
Associate Chairman, Department of Radiation Oncology
Harper Hospital
Representing: Barbara Ann Karmanos Cancer Institute

Tanina Foster
Project Coordinator
Barbara Ann Karmanos Cancer Institute

Debra M. Fox, M.A., R.N.
Director, Personal Health Services
Allegan County Health Department
Representing: Michigan Association for Local Public Health

Carol Franck, M.S., R.N.
Executive Director
Michigan Nurses Association

Jean Friend, R.D., M.P.A.
Office of Services to the Aging
Michigan Department of Community Health

Richard E. Gallagher, Ph.D.
Professor, Department of Family Medicine
Wayne State University
Representing: Barbara Ann Karmanos Cancer Institute

Carol Garlinghouse, M.S.N., R.N.
Cancer Prevention and Control Section
Michigan Department of Community Health

Charles Gayney
Director, Social Security Department
International Union UAW

Carol L. Genee
Michigan Public Health Institute

Barbara A. Given, Ph.D., R.N.
Associate Director, Institute for Managed Care
Professor, College of Nursing
Michigan State University
Representing: Michigan Nurses Association

C. William Given, Ph.D.
Professor, Department of Family Practice
College of Human Medicine
Michigan State University

Elizabeth Gleicher
Attorney at Law
Gleicher and Petk, P.C.

Therese Green, M.H.S.
Director of Health Education
Northern Michigan Hospital

Janice Gross, M.P.H.
Michigan Public Health Institute

Peter G. Gulick, D.O.
Associate Professor of Internal Medicine
College of Osteopathic Medicine
Michigan State University

Hope K. Haefner, M.D.
Associate Professor of Obstetrics/Gynecology
University of Michigan
Representing: Michigan Cervical Cancer Advisory Committee

Polly Hager, M.S.N., R.N.
Michigan Public Health Institute

Hiam Hamadi, R.N.
Arab Community Center for Economic and Social Services (ACCESS)

Jonnie Hamilton, R.N.
Michigan Black Nurses Association, Detroit Chapter

Shelly Hamlin
General Motors Corp.

Adnan Hammad, Ph.D.
Health Services Director
Arab Community Center for Economic and Social Services (ACCESS)

Carl Hammerstrom, M.D.
Representing: Michigan State Medical Society

Linda Harrison, R.N.
Representing: Michigan Nurses Association

Lucy Harrison, R.N.
American Indian Health and Family Services of Southeastern Michigan

Rick Haverkate, M.P.H.
Director of Health Services
Inter-Tribal Council of Michigan, Inc.

Sue Haviland, M.S.N.
Cancer Prevention and Control Section
Michigan Department of Community Health

Charlotte M. Hewitt
Inter-Tribal Council of Michigan, Inc.

Benjamin E. Hill
Vice President
Center for Health Affairs

Joanne G. Hogan, Ph.D.
Epidemiology Services Division
Michigan Department of Community Health

Barbara Hollie, R.N., M.S.N.
Barbara Ann Karmanos Cancer Institute

Susanne Homant, M.B.A.
Executive Director
Michigan Hospice and Palliative Care Organization

Susan Hoppough, M.S.N., R.N.
Institute for Managed Care
Michigan State University

William Hryniuk, M.D.
Director, Breast Program
Barbara Ann Karmanos Cancer Institute

Carol L. Isaacs, R.N., J.D.
Health Legislation and Policy Development
Michigan Department of Community Health

Jay Jackson
Director
Greater Detroit Area Health Council

Gary Jeffers, D.M.D.
Associate Professor, School of Dentistry
University of Detroit-Mercy

Lonnie Johnson
African-American Male Initiative
Michigan Department of Community Health

Shawn Johnson Fulton, Ph.D.
Marriage and Family Therapist

Mary Jim Josephs, Ph.D.
College of Education
Michigan State University
Representing: American Cancer Society, Great Lakes Division, Inc.

Andrew M. Kelahan, Ph.D.
Chief Operating Officer
Coalition of National Cancer Cooperative Groups

Kevin A. Kelly
Managing Director
Michigan State Medical Society

Lisa King, M.H.S.A.
Administrative Manager, Josephine Ford Cancer Center
Henry Ford Health System

Steven Klein, M.D.
Providence Health
Representing: Michigan Academy of Family Physicians

Janice Klos, C.A.E.
Chief Executive Officer
Michigan Academy of Family Physicians

Katherine Knoll
Director of Public Advocacy
American Heart Association

Jeanne Knopf DeRoche, M.A.
Representing: Tobacco-Free Michigan Action Coalition

Barbara Kopasz
Associate Vice President
Health Alliance Plan

Andrew D. Kruse, M.S.
Director, Office of Health Promotion and Disease Prevention
Genesys Health System

Mary LaVoy, R.N.
Quality Coordinator
Physicians Health Plan

Fred Lee, M.D.
Prostate Cancer Center
Crittenton Hospital
Representing: Michigan Prostate Cancer Advisory Committee

Nancy Lefkowitz, R.N.
Administrator, Health Education
SelectCare HMO

Ellen Leroi, Ph.D.
Marriage and Family Therapist

Jeffrey Letzer, D.O.
Representing: Michigan Osteopathic Association

Yvonne Lewis
Project Administrator
Flint & Vicinity Action Community and Economic Development

Jeanette Lightning, M.P.H.
Women's & Reproductive Health Unit
Michigan Department of Community Health

Jeff Livermore, M.S.A.
Director, Information Services
Barbara Ann Karmanos Cancer Institute

Kathleen Longo, M.D., M.P.H.
Center for Health Outcomes/Evaluation
Representing: Michigan Peer Review Organization

Ray Lord, M.D.
Clinical Research Director
West Michigan Cancer Center
Representing: Kalamazoo Community Clinical Oncology Program

Carroll Lutz, M.A.
Consultant
Michigan Nurses Association

Mary Malloy
Executive Director
Michigan Society of Hematology and Oncology

Debra Mattison, M.S.W.
Representing: Michigan Association of Social Workers in Health Care

Nicholas Maynard, M.A.
Michigan Public Health Institute

Allen McBride, M.D.
Senior Associate Medical Director for Medical & Benefit Policy Administration
Blue Cross Blue Shield of Michigan

Michelle McDevitt
Program Director
Michigan Capitol Girl Scout Council

Harry McGee, M.P.H.
Epidemiology Services Division
Michigan Department of Community Health

Karen McGettigan
Smoking Cessation Analyst
Borgess Medical Center

Joan McGowan, R.D.H., Ph.D.
Associate Professor, School of Dentistry
University of Michigan
Representing: Michigan Spit Tobacco Education Program

Bradley K. McKinney, M.P.H., M.S.W.
Michigan Public Health Institute

Duane Mezwa, M.D.
Department of Radiology
William Beaumont Hospital
Representing: Michigan Radiological Society

Dianne Miller
Associate Executive Director
Michigan Pharmacists Association

Sherry Mirasola
Corporate Communications
Michigan Health and Hospital Association

Dan Mishkin
Michigan Hospice and Palliative Care Organization

Kalyani Misra, M.D., M.P.H.
Medical Director
Lapeer County Health Department
Representing: Genesee County Medical Society & Michigan State Medical Society

Ruth A. Mohr, R.N., M.P.H., Ph.D.
Michigan Public Health Institute

James Montie, M.D.
Head, Section of Urology
University of Michigan
Representing: Michigan Prostate Cancer Advisory Committee

James Moore
Director of Programs
American Lung Association
Representing: Michigan Lung Cancer Advisory Committee

James Moseley, M.D., Ed.D., L.P.C.
Associate Professor, Community Medicine
Wayne State University

Barbara Moss, M.A.
East District Supervisor, Sexually Transmitted Disease Program
Michigan Department of Community Health

Carol Munsell , M.S.A., R.N.
Representing: Michigan Hospice and Palliative Care Organization

Penny Murphy, R.N.C., C.R.N.H.
St. John's Health System
Representing: Michigan Hospice and Palliative Care Association

Loretta Neville, M.S.A., R.N.
Michigan Public Health Institute

Franz Newbrecht, M.S.
Michigan Pharmacists Association

Mary Noel, M.P.H., Ph.D., R.D.
Associate Professor, College of Human Medicine
Michigan State University
Representing: Michigan Colorectal Cancer Advisory Committee

Wendy Nye
Health Education
Genesee County Health Department

Harold Oberman, M.D.
Professor of Pathology
University of Michigan
Representing: Michigan Breast Cancer Advisory Committee

Carol Ogan
Community Living, Children and Families
Michigan Department of Community Health

Karen S. Ogle, M.D.
Director, Palliative Care Education and Research
Cancer Center at Michigan State University

Timothy O'Rourke, M.D.
Cancer and Hematology Centers of West Michigan
Representing: Grand Rapids Community Clinical Oncology Program

Robert Parrish
Senior Vice President
Greater Detroit Area Health Council

Jeanne Parzuchowski, R.N., M.S., O.C.N.
Vice President, Research
Hospice of Michigan

Lawrence Pawl, M.D.
President
Medical Specialty Associates
Representing: Michigan State Medical Society

Ralph Pearlman, M.D.
Private Practice

William Peebles, M.P.H.
African-American Male Initiative
Michigan Department of Community Health

Susan Penl, R.N., B.A.
Ingham Hospice

Giovannino Perri, M.D.
Medical Services Administration
Michigan Department of Community Health

William P. Peters, M.D., Ph.D.
President, Director and Chief Executive Officer
Barbara Ann Karmanos Cancer Institute

Laura Peterson, M.A.
Program Manager, Breast and Cervical Cancer Control Program
Ingham County Health Department
Representing: Michigan Association for Local Public Health

Tom Peterson, M.D.
Spectrum Health System

John L. Pfenninger, M.D.
Private Practice
Clinical Professor of Family Medicine, Michigan State University
Director, The Medical Procedures Centers, P.C.
President, The National Procedures Institute
Representing: Michigan Academy of Family Physicians

Tess Pido, R.N.
Representing: Asian Pacific Organization

Noel Pingatore, B.S.
Health Education Program Coordinator
Representing: Inter-Tribal Council of Michigan, Inc.

Sharon Popp, Ph.D., M.S.W.
Instructor, Occupational and Environmental Medicine
Wayne State University

Kay Pru'dhomme, R.N., B.S.N.
Representing: Michigan Association for Local Public Health

Ann Rafferty, Ph.D.
Epidemiological Services Division
Michigan Department of Community Health

Victoria A. Rakowski, R.N., E.T.
Vice President, Cancer Control
American Cancer Society, Great Lakes Division, Inc.

Carol Rapson, M.D.
Medical Oncologist
Medical Director, Hospice House of Mid-Michigan
Medical Director, Clinton/Ingham County Hospice
Representing: Michigan Society of Hematology and Oncology

Dolores Rawlings, R.N., B.S.
Borgess Medical Center
Representing: Kalamazoo Black Nurses Association

Murray Rebner, M.D.
Co-Director, Breast Imaging
Department of Diagnostic Radiology
William Beaumont Hospital
Representing: Michigan Radiologic Society

Sonnora Reed, D.O.
Medical Director
Hospice of Michigan

Mathew Reeves, B.V.Sc., Ph.D.
Director, Epidemiological Services Division
Michigan Department of Community Health

Virginia Hill Rice, Ph.D., R.N.
Professor, College of Nursing
Wayne State University
Representing: Michigan Nurses Association

Joan Rodney
General Motors Corp.

Abby Rosenthal, M.P.H.
Program Manager
Health Alliance Plan

Jody Ross
Co-Director, Michigan Center for Rural Health
Michigan State University

Mary Elizabeth Roth, M.D., M.S.A.
Representing: Michigan Academy of Family Physicians

Kenneth S. Rudman, M.D.
Chair, Task Force on Pain Management
Representing: Michigan State Medical Society

Phyllis Rule
President
Michigan Education Association, Retirees

Charles Schiffer, M.D.
Chief for Division of Hematology/Oncology
Wayne State University
Director, Clinical Research
Representing: Barbara Ann Karmanos Cancer Institute

Stephanie Schim, Ph.D., R.N.
Henry Ford Health System
Representing: Michigan Public Health Association

Carolyn Schmidt, R.N., M.S., O.C.N.
Administrative Manager, Clinical Trials
Josephine Ford Cancer Center
Henry Ford Health System

Aaron P. Scholnik, M.D.
Associate Professor, Division of Hematology/Oncology
Michigan State University
Representing: Upper Peninsula Health Care Network

David Schottenfeld, M.D.
Professor, Department of Epidemiology
School of Public Health
University of Michigan

Sheldon Schwartz
Representing: Michigan Prostate Cancer Advisory Committee

John A. Scott, M.P.A.
Director of Health & Community Resources
Muskegon County Health Department

Kim Sibilsky
Executive Director
Michigan Primary Care Association

Samuel M. Silver, M.D., Ph.D.
Medical Director, University of Michigan Cancer Center Network
University of Michigan Comprehensive Cancer Center

Ellen Sprentall-Nankervis, Pharm.D.
National Accounts Manager, Health Economics
Amgen, Inc.

Erik J. Stalhandske, M.P.P., M.H.S.A.
Marketing Manager
Michigan Peer Review Organization

Sally Steiner, M.S.W., C.S.W.
Senior Policy Analyst, Office of Services to the Aging
Michigan Department of Community Health

Philip Stella, M.D.
Ann Arbor Regional Community Clinical Oncology Program and McAuley Cancer Center
Representing: Michigan Society of Hematology and Oncology

Margaret Steslicki, R.N.
Breast and Cervical Cancer Control Program
Saginaw Chippewa Indian Tribe
Representing: Inter-Tribal Council of Michigan, Inc.

Toni Stevenson, R.N., M.S.
Director, Continuum of Care
Ingham Regional Medical Center
Representing: Michigan Nurses Association

Judy L. Stewart
Tobacco Policy Manager
Representing: American Cancer Society, Great Lakes Division, Inc.

Bertram Stoffelmayr, Ph.D.
Professor, Department of Psychiatry
Representing: Cancer Center at Michigan State University

Sheryl L. Stogis, Dr.P.H.
Chief Executive Officer
Michigan Peer Review Organization

Heather Story, M.P.H.
Michigan Public Health Institute

Christopher Surrell, B.A., M.P.A.
Special Assistant to the Director
Michigan Department of Community Health

Howard Sutton
Vice President, Corporate Relations
Steelcase

G. Marie Swanson, Ph.D., M.P.H.
Director
Cancer Center at Michigan State University

Don Sweeney, M.A.
Manager, School Health Unit
Michigan Department of Community Health

Connie Szczepanek, R.N., B.S.N.
Administrative Director
Grand Rapids Community Clinical Oncology Program

Sheila Tann, R.N., N.D.
Inter-Tribal Council of Michigan, Inc.

Dan Thompson
Chief Operating Officer
Michigan Primary Care Association

Dianne Thompson, M.D.
Providence Cancer Center

Barbara A. Threatt, M.D.
Medical Director
Comprehensive Breast Centers
Representing: Michigan State Medical Society

Ashutosh Tiwari, M.D.
Josephine Ford Cancer Center
Henry Ford Health System

Timothy J. Tobolic, M.D.
Family Physician, Private Practice
Byron Family Medicine, P.C.
Representing: Michigan Academy of Family Physicians

Bruce Trevithick
Director, Community Relations
Healthcare Council of Mid-Michigan
Representing: Michigan Health and Hospital Association

Irene Turkewycz, B.S.N., M.Ed.
Associate Director, Center for Health Promotion and Disease Prevention
Henry Ford Health System

Sommai Ung Zirkel
Clinical Service Line Operations
Barbara Ann Karmanos Cancer Institute

Vainutis Vaitkevicius, M.D.
Professor Emeritus, Wayne State University
Representing: Barbara Ann Karmanos Cancer Institute

Claudia Valdez-Lowe, R.N., B.S.N.
Representing: National Association of Hispanic Nurses, Michigan Chapter

Paulette M. Valliere, Ph.D.
Cancer Prevention and Control Section
Michigan Department of Community Health

Gregg K. VandeKieft, M.D.
Assistant Professor, Department of Family Practice
College of Human Medicine
Michigan State University

Dorothy Vaughan, M.A., R.D.
Public Health Nutritionist
Macomb County Health Department
Representing: Michigan Dietetic Association

William Wadland, M.S., M.D.
Professor and Chair, Department of Family Practice
College of Human Medicine
Michigan State University
Representing: Cancer Center at Michigan State University

Kenneth Warner, Ph.D.
Professor, School of Public Health
University of Michigan

John Wei, M.D.
Assistant Professor of Urology/Surgery
University of Michigan

Susan Weinberg, B.S.
Assistant Director, Health Education
Barbara Ann Karmanos Cancer Institute

Linda Weiss, Ph.D.
Director, Metropolitan Detroit Cancer Surveillance System
Barbara Ann Karmanos Cancer Institute

Joan Westendorp, R.N., B.S.N., O.C.N.
Director of Research
West Michigan Cancer Center
Representing: Oncology Nursing Society, Greater Kalamazoo Chapter

Nancy White, R.N., M.S., A.O.C.N.
Outcomes Coordinator
West Michigan Cancer Center
Representing: Oncology Nursing Society

Mikelle Whitt, M.A.
Tobacco Section
Michigan Department of Community Health

Max Wicha, M.D.
Director
University of Michigan Comprehensive Cancer Center

Richard Wimberley
Michigan Public Health Institute

Billie Wimmer
State Director
Office of U.S. Senator Spencer Abraham

May Yassine, Ph.D.
Michigan Public Health Institute

Mei-yu Yu, Ph.D.
Director, Healthy Asian Americans Project
School of Nursing
University of Michigan

Cynthia Zane, R.N., Ed.D.
Dean, College of Health Professions
University of Detroit-Mercy

Thomas Zuber, M.D.
Program Director, Family Medicine
Saginaw Cooperative Hospitals
Representing: Michigan State Medical Society

Appendix B:

Michigan Cancer Consortium

Michigan Cancer Consortium

ACCESS Community Health Center
Adnan Hammad, Ph.D.
Health Services Director

American Cancer Society, Great Lakes Division, Inc.
Victoria A. Rakowski, R.N., E.T.
Vice President, Cancer Control
(Consortium Co-Chair, Member of the MCC Executive Committee)

American College of Surgeons
Alfred E. Chang, M.D.
Professor of Surgery
University of Michigan Health System

Barbara Ann Karmanos Cancer Institute
William P. Peters, M.D., Ph.D.
President, Director and Chief Executive Officer
(Member of the MCC Executive Committee)

Blue Cross Blue Shield of Michigan
Allen McBride, M.D.
Senior Associate Medical Director for Medical and Benefit Policy Administration

Cancer Center at Michigan State University
G. Marie Swanson, Ph.D., M.P.H.
Director
(Member of the MCC Executive Committee)

Flint & Vicinity Action Community and Economic Development
Yvonne Lewis
Program Administrator

Grand Rapids Community Clinical Oncology Program
Timothy O'Rourke, M.D.
Cancer and Hematology Centers

Health Alliance Plan
Barbara Kopasz
Associate Vice President, Market Support and Business Relations

Henry Ford Health System
Raymond Y. Demers, M.D., M.P.H.
Director, Josephine Ford Cancer Center

Hospice of Michigan
John W. Finn, M.D.
Executive Medical Director

Inter-Tribal Council of Michigan, Inc.
Rick Haverkate, M.P.H.
Director of Health Services

Michigan Academy of Family Physicians
Mary Elizabeth Roth, M.D., M.S.A.
Past President

Michigan Association for Local Public Health
Mark J. Bertler, B.A., C.A.E.
Executive Director

Michigan Black Nurses Association
Dorothy Brown, R.N.
Past President

Michigan Dietetic Association
Dorothy Vaughan, M.A., R.D.
Public Health Nutritionist
Macomb County Health Department

Michigan Health and Hospital Association
Roxanne Clark, M.P.A., F.A.A.M.A.
Corporate Director, Cancer Care Services
McLaren Regional Cancer Center

Michigan Hospice and Palliative Care Organization
Susanne Homant, M.B.A.
Executive Director

Michigan Nurses Association
Virginia Hill Rice, Ph.D., R.N.
Professor, College of Nursing
Wayne State University

Michigan Osteopathic Association
Peter G. Gulick, D.O.
Associate Professor of Internal Medicine
College of Osteopathic Medicine
Michigan State University

Michigan Peer Review Organization
Sheryl L. Stogis, Dr.P.H.
Chief Executive Officer

Michigan Primary Care Association
Kim Sibilsky
Executive Director

Michigan Radiological Society
Jeffrey David Forman, M.D.
Associate Chairman, Department of Radiation Oncology
Harper Hospital

Michigan Society of Hematology and Oncology
Carol Rapson, M.D.
Medical Director, Hospice House of Mid-Michigan
Medical Director, Clinton/Ingham County Hospice

Michigan State Medical Society
Lawrence Pawl, M.D.
President, Michigan Specialty Associates

National Association of Hispanic Nurses, Michigan Chapter
Connie Alfaro, R.N., M.P.H., M.S.
Division of Community Services
Michigan Department of Community Health

Oncology Nursing Society
Nancy White, R.N., M.S., A.O.C.N.
Outcomes Coordinator
West Michigan Cancer Center

University of Michigan Comprehensive Cancer Center
Max Wicha, M.D.
Director
(Member of the MCC Executive Committee)

University of Michigan School of Public Health
David Schottenfeld, M.D.
Professor, Department of Epidemiology
University of Michigan-School of Public Health

Upper Peninsula Health Care Network, Inc.
Aaron P. Scholnik, M.D.
Associate Professor, Division of Hematology/Oncology
Michigan State University
(Consortium Co-Chair, Member of the MCC Executive Committee)

West Michigan Cancer Center
Ray Lord, M.D.
Clinical Research Director

Members-at-Large:

Deanna A. Beyer, R.N., M.S.N.
Nurse Manager
University of Michigan

Donald G. Bronn, M.D., Ph.D.
Medical Director
Michigan Institute for Radiation Oncology